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**Development and Evaluation of a Smartphone-enabled, Carer-supported
Educational Intervention for Management of Disabilities Following Stroke
in India**

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**Thesis submitted in accordance with the requirements for the degree of
Doctor of Philosophy**

University of London

DECEMBER 2015

Department of Clinical Research

Faculty of Infectious and Tropical Diseases

LONDON SCHOOL OF HYGIENE & TROPICAL MEDICINE

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2. International Centre for Evidence in Disability, LSHTM.**

DECLARATION OF OWN WORK

I, SURESH KUMAR KAMALAKANNAN, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.



SURESH KUMAR KAMALAKANNAN

DECEMBER 2015

Abstract

Background

The incidence and prevalence of stroke in India has reached epidemic proportions and is considered a major public health problem. Given the nature of the condition, affected individuals often become disabled, with profound effects on their quality of life. This study aimed to develop an educational intervention for management of post-stroke disability in India and to evaluate the feasibility and acceptability of delivering this intervention using Smartphone technology and caregiver support.

Objectives

- To systematically develop a Smartphone-enabled, carer-supported, educational intervention that is multi-disciplinary, patient-centred and culturally-sensitive for management of disabilities following stroke in India.
- To evaluate the feasibility and acceptability of the intervention by stroke survivors and their caregivers in the Indian context.

Methodology

The study was conducted in Chennai, India, and was implemented in three phases:

Phase 1: Development of the intervention

Phase 2: Field-testing and finalising of the intervention

Phase 3: Piloting of the intervention and assessment of feasibility and acceptability.

A mixed methods approach was used to develop and evaluate the intervention.

Results

The intervention was systematically developed and titled ‘Care for Stroke’. It was delivered through a web-based, Smartphone-enabled application. During field-testing, key uncertainties, such as issues with connectivity, video streaming, picture clarity, quality of the videos and functionality of the application, were identified. The intervention was reviewed, revised and finalised before pilot-testing. Findings from the pilot-testing showed that the ‘Care for Stroke’ intervention was feasible and acceptable in an Indian context. Over 90% of the study participants felt that the intervention was relevant, comprehensible and useful. About 95% of the stroke survivors and all the caregivers (100%) rated the intervention to be excellent, based on its overall credibility, usability and user-friendliness.

Discussion

‘Care for Stroke’ is an innovative educational intervention that can empower stroke survivors and their families to be cognisant of their disability, ways to manage it and how to make appropriate decisions on their road to recovery. The current context for stroke rehabilitation provides a reasonable opportunity for public health practitioners to optimise interventions such as ‘Care for Stroke’ to efficiently bridge the gaps in accessibility of stroke rehabilitation services and enhance the continuum of care for stroke survivors worldwide. The intervention is specifically pertinent to India and many other Low and Middle-Income Countries (LMICs) where resources for improving access to stroke rehabilitation services are inadequate.

Conclusion

‘Care for Stroke’ is an innovative effort towards the global need for research to develop interventions that bridge the barriers to the provision of stroke rehabilitation services and meet the needs of affected individuals. This application and similar approaches that harness

the potential of current technology need to be researched further to bridge the gaps in access to stroke services worldwide.

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Abbreviations

AAP:	Adelaide Activities Profile
ADL:	Activities of Daily Living
AHA:	American Heart Association
ASA:	American Stroke Association
BI:	Barthel Index
CBR:	Community-Based Rehabilitation
CDN:	Content Delivery Network
CT:	Computerised Tomography
DALYs:	Disability-Adjusted Life Years
DAS:	Disability Assessment Schedule
DRS:	Disability Rating Scale
Euro QOL:	Euro Quality of Life
FAD:	Family Assessment Device
FAI:	Frenchay Activities Index
FES:	First Ever Stroke
FIM:	Functional Independence Measure
FSE:	Functional Status Examination
GBD:	Global Burden of Diseases
GOSE:	Glasgow Outcome Scale Extended
HICs:	High-Income Countries
HISCL:	Head Injury Symptom Checklist
HRQOL:	Health-Related Quality of Life
ICF:	International Classification of Functioning Disability and Health
LAMP:	Linux Apache My SQL PHP
LMICs:	Low and Middle-Income Countries
MeSH:	Medical Subject Headings
mHEALTH:	Mobile Health
MRC:	Medical Research Council
MRS:	Modified Rankin Scale
NCD:	Non-Communicable Diseases
NICE:	National Institute of Clinical Excellence
NIHSS:	National Institute of Health Stroke Scale
NPCDCS:	National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Disease and Stroke
OAD:	Observer Assessment of Disability
PARS:	Personal Adjustment and Role Skills Scale
PHP:	PHP Hypertext Processor
PQOL:	Perceived Quality of Life
RCT:	Randomised Controlled Trial
SASIP:	Stroke Adapted Sickness Impact Profile
SD:	Secured Digital
STEPS:	STEPwise Approach to Stroke Surveillance
STROBE:	Strengthening The Reporting of Observational studies in Epidemiology
TIA:	Transient Ischaemic Attack
WHO:	World Health Organization

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Thesis Outline

This thesis is presented in the “research paper style” format, in accordance with the London School of Hygiene and Tropical Medicine research degree regulations. Much of the thesis includes a series of research papers / manuscripts which have been either published or submitted to peer-reviewed journals. This thesis is divided into seven chapters.

Chapter – 1 is the introductory chapter of the thesis with the rationale for the development and evaluation of a Smartphone-enabled, carer-supported educational intervention for management of disabilities following stroke in India. It also includes the aims and objectives of this PhD research study.

Chapter – 2 is on the research study methods which describes the protocol for the entire PhD research study.

Chapter – 3 comprises of two systematic literature reviews that were carried out as a part of the PhD. The epidemiology of stroke in India was systematically reviewed (Chapter 3.1) and the challenges experienced in understanding the epidemiology of stroke and other acquired brain injuries in India were separately documented (Chapter 3.2). Another global systematic review was conducted to assess the evidence for educational interventions in managing disabilities following stroke and other acquired brain injuries (Chapter 3.3).

Chapters 4, 5 and 6 are the three major chapters which describe the results of this PhD research study. Chapter - 4 elaborates the results from a rehabilitation needs assessment study that was conducted to inform the development of the intervention. Chapter - 5 provides a

detailed account of the ‘Care for Stroke’ intervention and its systematic development. Results of the phased evaluation of the ‘Care for Stroke’ intervention in an Indian context are detailed in Chapter - 6.

Chapter – 7 is the chapter on discussion of the results from this PhD research study. It includes the study conclusions and recommendations. Bibliography and Appendices are included after Chapter - 7.

Chapter 1

Introduction to the Problem and Rationale for the Study

Preamble

This chapter provides a general overview of stroke, including the types of stroke, risk factors, global epidemiology and the disabling effects of stroke among those affected. It also describes the existing gaps in the provision of stroke care and accessibility to stroke rehabilitation services in India and in similar contexts. The last part of this chapter explains the potential strategies for bridging these gaps especially in the context of Low and Middle Income Countries and justifies the rationale for this doctoral research study.

Introduction to the Problem and Rationale for the Study

1.1 What is Stroke?

Stroke is clinically defined by the World Health Organization (WHO) as ‘the rapid development of clinical signs and symptoms of a focal neurological disturbance lasting more than 24 hours or leading to death with no apparent cause other than a vascular origin’¹.

A person experiences a stroke when a blood clot blocks a blood vessel in the brain or a vessel that supplies it, or when there is bleeding in the brain. The interruption of blood supply to the brain reduces the supply of oxygen and nutrients to it, causing injury and death of the brain tissue². This brain damage may subsequently result in the long-term disability or death of an affected individual².

1.2 Types of Stroke

Based on the pathophysiology of brain damage, stroke is broadly classified into Ischaemic stroke and Haemorrhagic stroke. Ischaemic strokes occur when an artery supplying blood to the brain is blocked. The blockage can be either due to a thrombus at the site of occlusion or formed in another part of the circulation (embolus)³. Ischaemic strokes account for nearly 80% of all strokes worldwide⁴. Haemorrhagic stroke occurs when a blood vessel ruptures and bleeds into the surrounding brain. The bleeding can occur within the brain tissue (intra-cerebral) or can occur in the space between the meninges (sub-arachnoid)⁵. Haemorrhagic strokes account for about 20% of all strokes worldwide⁴. Brain damage in haemorrhagic stroke is usually much more severe and more likely to be fatal compared to an ischaemic stroke².

1.3 Risk Factors for Stroke

There are various modifiable and non-modifiable risk factors for stroke⁶. The non-modifiable risk factors include age, sex, race, ethnicity and genetic factors⁶. Age is the single most important risk factor for stroke. Studies on stroke risk factors have shown that, for each successive 10 years after the age of 55, the stroke rate doubles in both men and women⁶. Stroke incidence rates are 1.25 times higher in men, but, because women tend to live longer than men, more women than men die of stroke each year⁶. Earlier studies on stroke genetics suggested that men whose mothers died of stroke and women who had a family history of stroke were at an increased risk of stroke⁶. Studies have also shown that Asians have a high risk of stroke⁶.

Prolonged exposure of an individual to certain modifiable risk factors can also increase the risk of developing a stroke. Modifiable risk factors include hypertension, smoking, obesity, excessive alcohol consumption, hyperlipidemia, diabetes, lack of physical activity, lack of a balanced diet, psycho- social stress and some cardiac causes⁶. These modifiable risk factors are associated with more than 90% of the risk of stroke⁷. Interventions targeted at these modifiable risk factors are expected to substantially reduce the risk of developing stroke (Table 1.1)⁸⁻⁹.

Table 1.1: American Stroke Association (ASA) Recommendations for Modifiable Behavioural Risk Factors⁹

Risk Factor	Recommendations	Class/Level of Evidence
Cigarette smoking	Healthcare providers should strongly advise every patient with stroke or TIA who has smoked in the past year to quit.	Class I; Level C
	It is advisable to avoid environmental (passive) tobacco smoke	Class IIa; Level C
	Counselling, nicotine products and oral smoking cessation medications are effective for helping smokers to quit.	Class I; Level A
Alcohol consumption	Patients with ischaemic stroke or TIA who are heavy drinkers should eliminate or reduce their consumption of alcohol	Class I; Level C
	Light to moderate levels of alcohol consumption (no more than two drinks per day for men and one drink per day for non-pregnant women) is sensible; non-drinkers should not be counselled to start drinking.	Class IIb; Level B
Physical activity	For patients with ischaemic stroke or TIA who are capable of engaging in physical activity, at least 30 minutes of moderate-intensity physical exercise, typically defined as vigorous activity sufficient to break a sweat or noticeably raise heart rate, one to three times a week (e.g. walking briskly, using an exercise bicycle) may be considered to reduce risk factors and comorbid conditions that increase the likelihood of recurrent stroke.	Class IIb; Level C
	For those individuals with a disability following ischaemic stroke, supervision by a healthcare professional, such as a physical therapist or cardiac rehabilitation professional, at least on the initiation of an exercise regimen, may be considered.	Class IIb; Level C
Metabolic syndrome	To date, the utility of screening patients for the metabolic syndrome after stroke has not been established.	Class IIb; Level C
	For patients who are screened and classified as having the metabolic syndrome, management should include counselling for lifestyle modification (diet, exercise and weight loss) for vascular risk reduction.	Class I; Level C
	Preventive care for patients with metabolic syndrome should include appropriate treatment for individual components of the syndrome that are also stroke risk factors, particularly dyslipidemia and hypertension.	Class I; Level A
Classes: Class I: Effective; Class IIa: Reasonably effective; Class IIb: Effectiveness unknown; Class III: Not recommended.		
Levels: Level A - Data derived from multiple clinical trials; Level B - Data derived from single clinical trial or non-randomised studies; Level C – Data from expert opinion or case studies		

1.4 Effects of Stroke

The most common presentation of a stroke is sudden weakness or numbness of the face, arm or leg, most often on one side of the body. Other symptoms include confusion, difficulty in speaking or understanding speech, blurred or poor vision in one or both eyes, loss of consciousness, difficulty in swallowing, and difficulty in walking, loss of balance and coordination¹⁰. If these symptoms last for less than 24 hours, it is called a Transient Ischaemic Attack (TIA)¹. Nearly a third of all strokes are preceded by a TIA¹¹. Stroke is associated with a wide variety of sensory-motor, cognitive-perceptual and behavioural impairments¹⁰. The effects of stroke will depend on the site of the brain lesion and severity of brain damage (Table 1.2)¹²⁻¹³. The effects of stroke can range from mild limb weakness (paresis) to spastic paralysis with severe cognitive dysfunctions¹³.

Severity of stroke is usually assessed using a standardised scale called the National Institute of Health Stroke Scale (NIHSS)¹⁴. The NIHSS is composed of 11 items, each of which scores a specific ability of the affected individual between '0 and 4'. A score of 0 typically indicates normal function in that specific ability, while a higher score is indicative of some level of impairment¹⁵. A stroke survivor can be classified to have minor, moderate, moderate-severe or severe stroke, according to the NIH stroke scale¹⁵. In addition to the primary impairments mentioned above, secondary complications developing as a result of impairments following stroke can hamper the recovery process¹⁶. Some of the common secondary complications of stroke are respiratory problems, postural hypotension, pressure sores, heterotrophic ossification, limb contractures and deformities¹⁰. The prognosis in stroke depends on the degree of primary impairments and secondary complications¹².

Table-1.2: Common stroke syndromes according to vascular distribution¹¹

Vascular Territory	Area Affected	Signs and Symptoms
Anterior cerebral artery	Frontal pole and medial frontal lobe	Contralateral: leg > face and arm weakness Frontal signs such as abulia
Middle cerebral artery	Posterior frontal, temporal, parietal lobes	Contralateral: face and arm > leg weakness, sensory loss to all modalities, visual field cut, visual-spatial neglect Ipsilateral: gaze preference Dominant hemisphere affected: aphasia, alexia, agraphia, acalculia
Posterior cerebral artery	Occipital lobe	Contralateral: homonymous hemianopia with thalamic involvement: sensory loss to all modalities or pain
Anterior inferior cerebellar artery	Lateral pontine syndrome	Contralateral: hemi-paresis and hemi-sensory loss of pain and temperature Ipsilateral: ataxia
Posterior inferior cerebellar artery	Lateral medulla (Wallenberg syndrome)	Contralateral: hemi-body pain and temperature loss Ipsilateral: facial pain, hemi-facial pain and temperature loss, ataxia, nystagmus, nausea/vomiting, vertigo, Horner's syndrome, Dysphagia, Hiccups.
Basilar artery	Pons (locked-in syndrome)	Bilateral: progressive quadriplegia, facial weakness Lateral gaze weakness with sparing of vertical gaze
Vertebral artery	Medial medulla	Contralateral: hemi-body weakness, loss of vibration and proprioception Ipsilateral: tongue weakness and/or atrophy
Vertebral artery	Lateral medulla	Wallenberg syndrome

1.5 Global Epidemiology of Stroke

Stroke is a major global public health problem. According to the Global Burden of Disease (GBD) study in 2010, stroke was the second leading cause of death worldwide¹⁷. Stroke alone accounted for 11% of all deaths worldwide in 2010. The GBD study showed a 26% increase in global stroke deaths over the past two decades, growing from 4.66 million deaths worldwide in 1990 to 5.87 million in 2010 (Table 1.3)¹⁷⁻¹⁹. According to this

study, these estimates are expected to rise further to 6.5 million stroke deaths annually by 2015 (Table 1.4)¹⁸⁻¹⁹. The increase in the incidence and prevalence of stroke in Low and Middle-Income Countries (LMICs) is attributed to the epidemiological transition and the increasing life expectancy²⁰.

Table 1.3: Global stroke deaths by types in 1990 and 2010 for all ages, both sexes combined and the percentage change

Condition	All ages stroke deaths (in 1000s)		
	1990	2010	Increase (%)
Ischaemic stroke	2241	2835	26.5
Haemorrhagic stroke & other non-Ischaemic	2419	3038	25.6
Total stroke	4660	5873	26.0
Source: Global burden of diseases study 2010 ¹⁷			

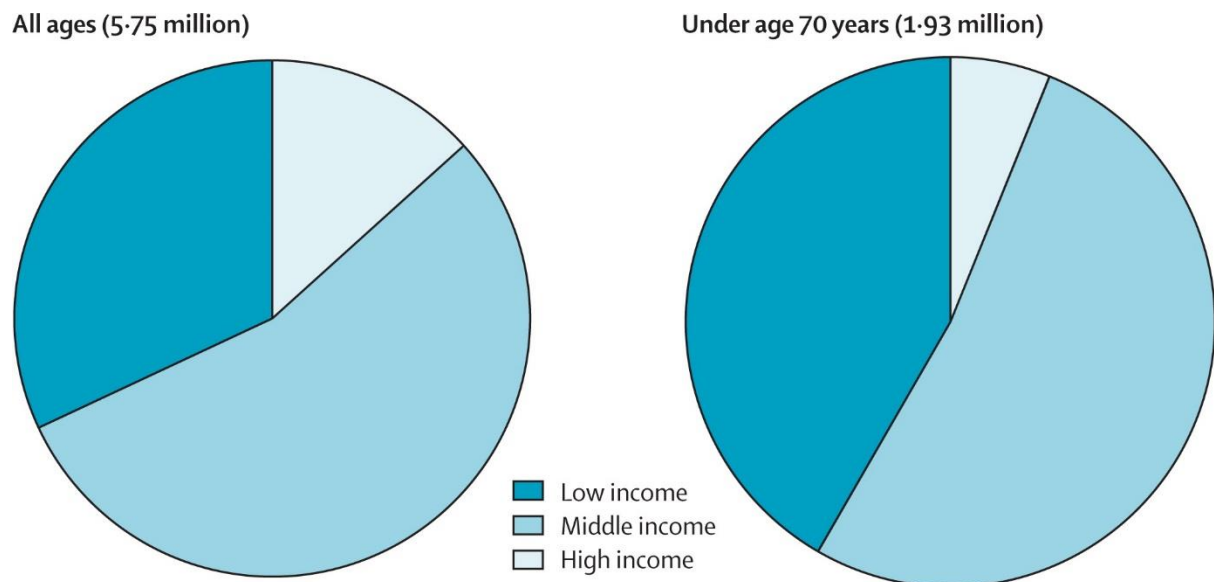
Table 1.4: Projected deaths for stroke, numbers and rates by age for 2010, 2015 and 2030

	Number (millions)			Rate per 1000		
	2010	2015	2030	2010	2015	2030
	Deaths					
0–59		0.8	0.8		0.1	0.1
60–69		1.2	1.3		2.5	2.0
70+		4.5	5.7		12.1	10.4
All ages	5.9	6.5	7.8	0.88	0.91	0.98
Source: Strong K, et al. Preventing stroke: saving lives around the world. <i>The Lancet Neurology</i> . 2007 ¹⁸⁻¹⁹ .						

According to the estimates from a progressive reassessment of the GBD study in 2005, over 85% of the global burden of stroke is borne by LMICs²¹. Figure 1.1 shows the percentage of stroke deaths by age and World Bank income group. Given the lack of

reliable reporting mechanisms and disease or death registration systems in LMICs, the epidemiological findings from the GBD study, for most of the LMICs, are likely to be underestimates²². The increase in incidence of stroke observed at the global level is also seen in LMICs. A recent systematic review of population-based stroke studies by Feigin et al in 2009²² documented that the incidence rate of stroke in LMICs has increased from 56/100,000 person-years during 1970-79 to 117/100,000 person-years during 2000-08²¹⁻²²

Figure 1.1: Percentage of stroke deaths by World Bank income group for all ages and for people under age 70 years



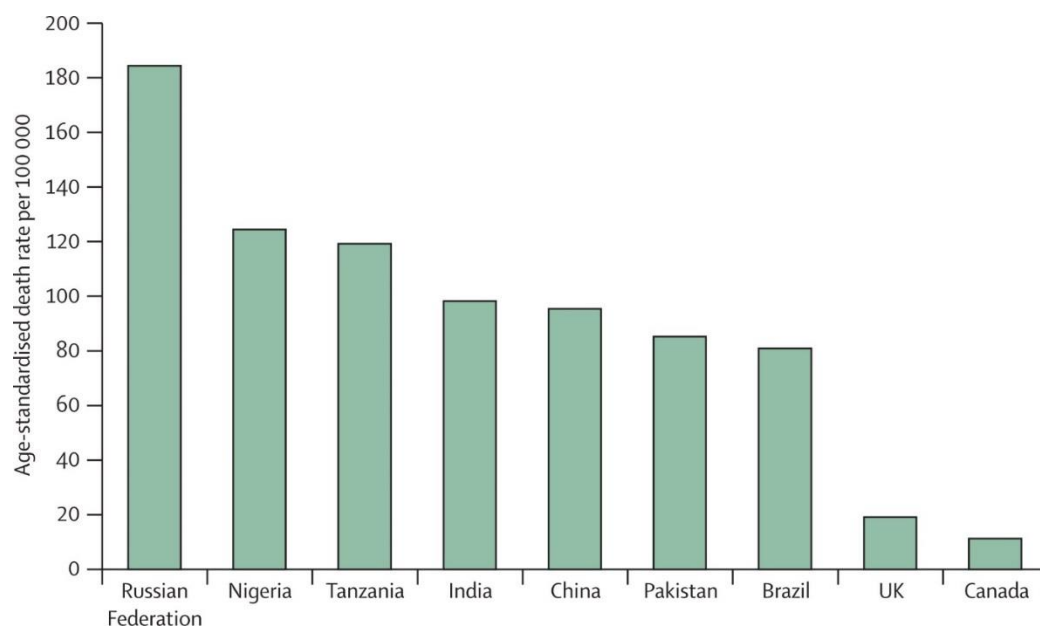
Source: Strong K, et al. Preventing stroke: saving lives around the world. *The Lancet Neurology*. 2007¹⁸

At the same time, this study has also shown a decrease in the stroke incidence from 163 per 100,000 person-years in 1970–79 to 94 per 100,000 person-years during 2000–08 in the High Income Countries (HIC)²². An important reason for this decrease is the efforts initiated by HICs towards primary and secondary prevention of stroke²². Figure 1.2 shows the death rates from stroke per 100,000 for ages 30–69 years in selected countries.

These findings indicate that an estimated 42% decrease in stroke incidence has occurred in HICs over the past four decades, alongside more than a 100% increase in LMICs during the same period. The review also documented the twofold increase in stroke incidence among the younger population (< 75 years) and fourfold increase in stroke incidence among the older population (> 75 years) in LMICs²².

In addition to reporting global stroke mortality rates, the GBD study documented that there were 30 million stroke survivors in 2010 and many people who survived a stroke experienced substantial disability¹⁷⁻²². According to the GBD ranking for Disability-Adjusted Life Years (DALY), stroke moved from 5th position in 1990 to 3rd position in 2010²³⁻²⁴.

Figure 1.2: Age-standardised death rates from stroke per 100,000 for ages 30–69 years, selected countries, projections for 2005



Source: Strong K, et al. Preventing stroke: saving lives around the world. *The Lancet Neurology*. 2007¹⁸

The global DALYs for stroke increased from 86.01 million in 1990 to 102.2 million in 2010, corresponding to an estimated 18.9% increase in the global DALYs for stroke over the past two decades (Table 1.5)²⁴. Thus, stroke is assuming epidemic proportions globally and the amount of disability following stroke is increasing worldwide¹⁷⁻²³. Given the lack of resources for stroke care and access to stroke services in LMICs, stroke is emerging as an important public health problem requiring urgent attention in these countries²⁵.

Table1.5: Global DALYs for stroke in 1990 and 2010 for all ages, both sexes combined and the percentage change

Condition	All ages DALYs (in 1000s)		
	1990	2010	Increase (%)
Ischaemic stroke	32128	39389	22.6
Haemorrhagic stroke	53882	62843	16.6
Total stroke	86010	102232	18.9
Source: Global burden of diseases study – 2010 ¹⁷			

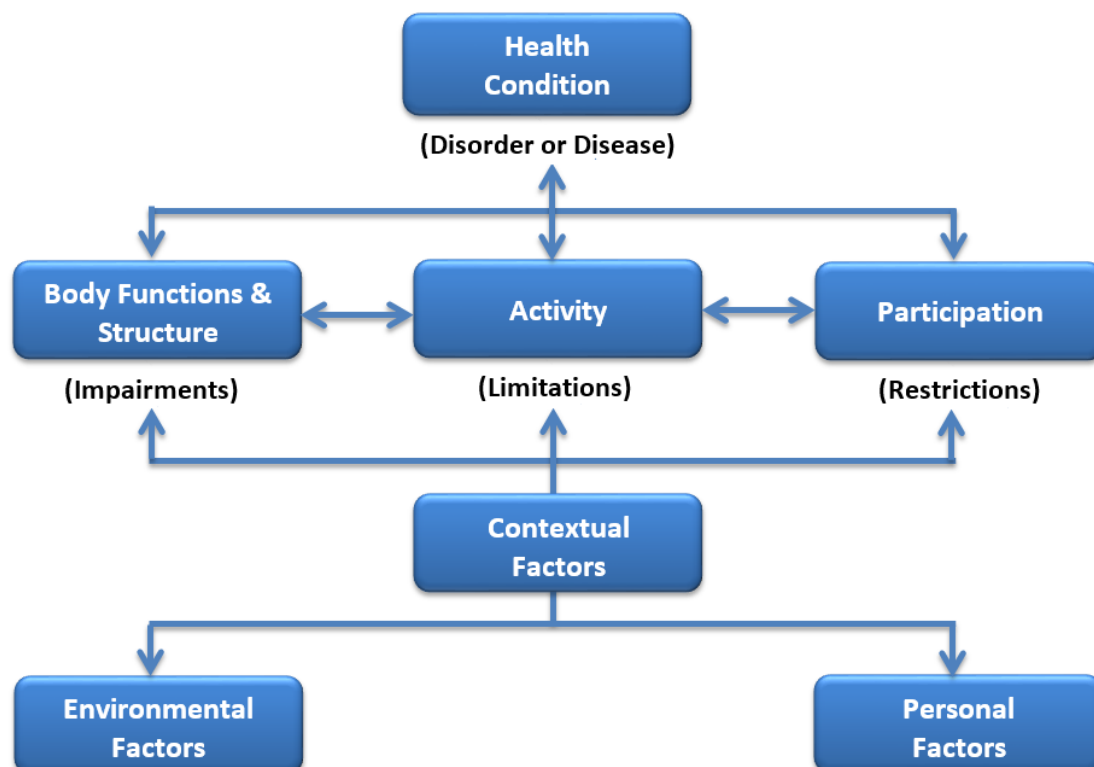
1.6 Disability Following Stroke

According to the International Classification of Functioning Disability and Health (ICF), disability is an umbrella term for impairments, limitation in activities and restriction in participation²⁶⁻²⁷. It is a complex process, reflecting the interaction between an individual with a health condition and the environment²⁷. For example, a stroke survivor may have mobility problems (impairment) that could reduce his/her opportunity to participate in social activities such as shopping and meeting friends (disability). However, the stroke survivor might be able to independently participate in most of his/her social activities with the help of a wheelchair. Although the impairment (mobility problems) of the stroke survivors is the same in the two aforementioned scenarios, the disability experienced by the

stroke survivor is minimised by the use of a wheelchair in the latter. Figure 1.3 and 1.4 illustrate the disability and functioning framework of any health condition²⁶.

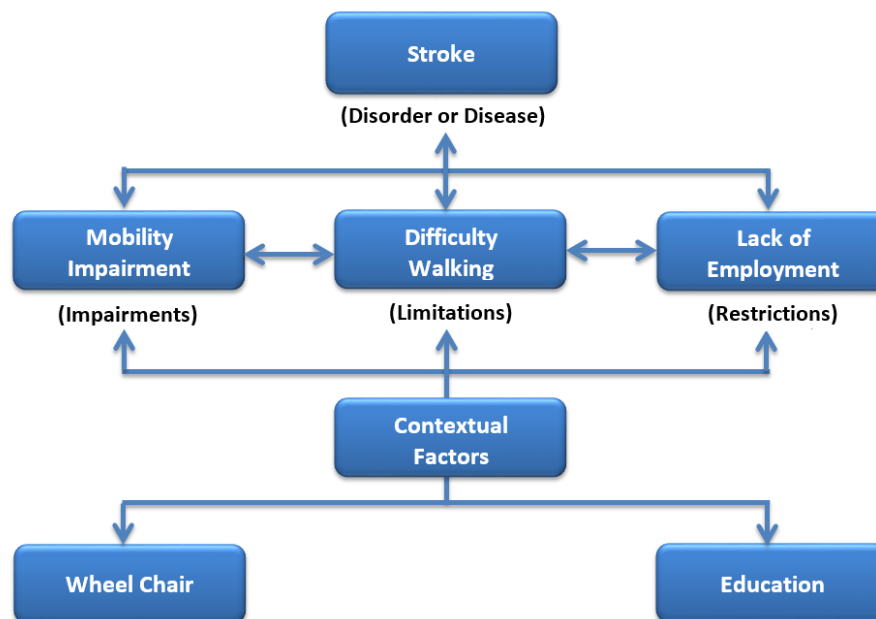
Disability following stroke is, therefore, not limited to impairments, but is the interaction between an individual with a condition (stroke survivor, in this case) and the environment in which he or she experiences a stroke²⁶. The severity of disability depends on the degree of impairment (physical, mental, cognitive) as well as the personal and contextual environment of the affected individual.

Figure 1.3: Framework for the description of health and health-related states by the ICF, World Health Organization.



The International Classification of Functioning, Disability and Health, WHO²⁶

Figure 1.4: Illustration of the ICF Framework with stroke as the health condition.



Adapted from the International Classification of Functioning, Disability and Health

Stroke impairment and environmental conditions can interact to limit the ability of the stroke survivor to independently perform his or her daily living activities. Consequently, it might also restrict effective participation of the stroke survivor in his/her family and social roles²⁷. Most often, stroke survivors become disabled with a profound effect on their quality of life²⁸.

The impact of disability following a stroke also affects the family of the stroke survivor²⁹. Adapting to the new role of ‘carer’ and adjusting to the sudden impact of stroke can be highly stressful for family members³⁰. The demand on caregivers increases tremendously when the stroke survivor experiences severe disability³¹. The rehabilitation needs of stroke survivors and their families vary extensively and are affected by many factors, such as the degree of impairment and the context in which the individual experiences a stroke²⁶⁻³².

1.7 Rehabilitation Needs of Stroke Patients

Given the disabling nature of the condition, stroke survivors usually have several kinds of rehabilitation needs in order to get back to their everyday life³³. The disability experienced by stroke survivors means that they might require assistance to independently perform their everyday activities, such as feeding, bathing, dressing, toileting and mobility³⁴. In addition to these physical needs, stroke survivors may also have difficulties in coping with the sudden changes in their life following a stroke³⁵. Stroke survivors may experience psychological problems such as depression and anxiety, due to these changes³⁶. Adjusting to life changes following a stroke is an important psychological need of stroke survivors³⁷.

From a social care perspective, stroke survivors might also require assistance with returning to work or finding a new job and participating effectively in their social roles³⁸. This is considered an essential long-term need after patients are discharged from the hospital and return to their community³⁹. The rehabilitation needs of stroke survivors will differ based on the severity of disability and the phase of recovery⁴⁰. Considering the ICF framework, rehabilitation needs are also expected to differ based on the environmental context in which one suffers a stroke (e.g. accessibility to rehabilitation services, socio-economic status, family support, etc.)²⁶.

Stroke rehabilitation is, therefore, an essential part of recovery after a stroke⁴¹. Appropriate rehabilitation is a rigorous process that involves assessment of the individual's needs following a stroke, setting specific, measureable, achievable goals for improvement,

provision of rehabilitation interventions to achieve the goals set, and review progress of such goals⁴². A core multidisciplinary stroke rehabilitation team would usually comprise of a consultant physician, nurses, physiotherapists, occupational therapists, speech therapists, clinical psychologists, a social worker and rehabilitation assistants with expertise in their respective professional disciplines⁴³. Members of the stroke rehabilitation team are usually expected to work as a team along with the stroke survivor and their family. Ideally, the entire team would work together to set therapeutic goals based on the felt needs of the stroke survivor and have an integrated approach to achieve the goals set⁴¹. Details regarding various stroke rehabilitation interventions and their recommendation in clinical guidelines are provided in Table 1.6

Table 1.6: Rehabilitation interventions and their recommendation in clinical guidelines⁴¹

Interventions	Goal	Recommendation Category	Grade of Recommendation
Beneficial or likely to be beneficial			
Multidisciplinary stroke-unit care	To improve independence	Recommended	A
Early supported discharge services	To improve independence	Recommended	A
Therapy-based rehabilitation services at home (within one year of stroke)	To improve ADL	Recommended	A, B
Outpatient rehabilitation services (day-hospital, community team)	To improve ADL	Selected Use	A, B
Rehabilitation services in long-term care settings	To improve ADL	Selected Use	B
Occupational therapy services	To improve ADL	Recommended	A, B
Occupational therapy services at home	To improve ADL & extended ADL	Recommended	A
Uncertain benefits			
Integrated-care pathways	To improve independence	Not recommended or Selected Use	B
Services with stroke liaison workers and participation	To improve independence	Not Mentioned	
Information provision	To improve knowledge and independence	Recommended	A

Therapy-based rehabilitation services at home (after one year)	To improve ADL	Selected Use	B, C
Speech and language therapy interventions	For aphasia	Recommended	B
Speech and language therapy interventions	For dysphagia	Recommended	B
Staff -led training Interventions	To improve oral hygiene	Selected Use	B
Cognitive rehabilitation	For spatial neglect	Selected Use	B
Unknown effect			
Cognitive rehabilitation	For attention deficits	Selected Use	B
Cognitive rehabilitation	For memory deficits	Selected Use	C
Cognitive rehabilitation	For motor apraxia	Selected Use	B, C
Interventions	For perceptual disorders	Selected Use	C
Occupational therapy	For cognitive impairment	Selected Use	C
Home-based intervention	For arm recovery	Not Mentioned	
Speech and language therapy	For speech apraxia	Recommended	C
Speech and language therapy	For dysarthria	Recommended	C
Goal setting in rehabilitation	To improve recovery	Not mentioned or Recommended	C
Behavioural therapies	For urinary incontinence	Recommended	C
Pre-discharge home assessments		Selected Use	
Guideline recommendation categories: recommended = recommended use for a substantial proportion of stroke patients; selected use = might be considered in selected patients or circumstances, not mentioned = no specific recommendation made; not recommended = not recommended for routine use (outside the context of a clinical trial).			
Guideline grade of recommendation categories: (A) = based on robust information from randomised trials that is applicable to the target population; (B) = based on less robust information (from experimental studies); (C) = consensus or expert opinion. ADL = activities of daily living			

1.8 Gaps in Post-stroke Rehabilitation in India

In HICs, the stroke survivors are supported by well-organised stroke rehabilitation services during their recovery⁴⁴. Organised stroke services are expected to reduce disability and enhance the chances of a stroke survivor returning to their own home⁴⁴. However, a recent follow-up study from HIC showed that 76% of a cohort of stroke survivors who got

discharged home from a stroke rehabilitation unit had not returned to work even after 12 months⁴⁵. This implies the need for improvement in stroke services, even in HICs. In LMICs, where the rehabilitation resources are very limited, there is lack of data on the rehabilitation needs of persons with disabilities following stroke²⁷.

The situation regarding post-stroke rehabilitation in India is also similar⁴⁶. Generally, People with disabilities encounter tremendous environmental barriers in accessing rehabilitation services in India⁴⁷. Lack of policy initiatives for rehabilitation, inadequate rehabilitation resources and health professionals, inaccessible environments and stigma are some of the barriers that persons with a disability experience⁴⁸. Taking into account the disabling effects of stroke and the existing environmental barriers to rehabilitation, the needs of stroke survivors in India are expected to be substantial and diverse.

In addition, rehabilitation services for persons with disabilities following stroke are inadequate⁴⁶. Rehabilitation services in India are usually hospital-based and driven predominately by physiotherapists⁴⁶. Therapy inputs from other health professionals (for example, occupational therapists and speech therapists) are rarely available to stroke patients⁴⁹. In addition, the informational needs of stroke patients and their primary caregivers to self-manage rehabilitation following stroke remain largely unfulfilled²⁷. A recent report on the national initiative for allied health sciences has documented a national shortage of 640,000 allied health professionals⁴⁹. According to the World Health Statistics (2011), there are six doctors per 10,000 people in India⁵⁰, while there are only three occupational therapists per 1,000,000 persons⁵¹.

There is no data on stroke rehabilitation services and centres, availability of services or utilisation of rehabilitation services by stroke survivors in India. Provision of rehabilitation services is usually limited to private hospitals located in urban areas and many people, especially those who are poor or live in rural areas, cannot afford to pay or have limited access to such services⁵². Patients and caregivers have to travel long distances to obtain rehabilitation services and the opportunity costs involved in accessing these services is also enormous²⁷. Although the number of private rehabilitation facilities in India has increased, these are only accessed by a tiny proportion⁵³. Most people with disabilities following stroke do not, therefore, have access to rehabilitation services in India⁵⁴. The existing barriers to rehabilitation suggest that the rehabilitation needs of stroke survivors in India remain largely unmet.

1.9 Strategies for Improving Access to Stroke Rehabilitation Services in LMICs – Evidence from Systematic Reviews

Evidence from systematic reviews and studies conducted in high-income countries (HICs) suggest that organised multidisciplinary, therapy-based rehabilitation services for stroke patients, provided at hospital or at patients' homes, improves their independence in terms of the personal activities of daily living⁵⁵⁻⁵⁷. Therapeutic multidisciplinary stroke rehabilitation services have been shown to enhance recovery and reduce patient dependency⁵⁵⁻⁵⁹. However, meeting the rehabilitation needs of stroke survivors in LMICs like India, with limited rehabilitation resources, is a challenging task. With the rising incidence of stroke and low availability of rehabilitation, it is imperative that we consider the development of cost-effective multi-dimensional stroke rehabilitation interventions. Some of the strategies for improving access to stroke rehabilitation services in LMICs and the evidence for such

strategies are discussed below. These include Community-based Rehabilitation, Self-Management, Educational Interventions and Smartphone-based Interventions.

1.9.1 Community-based Stroke Rehabilitation Strategy

Given the lack of access to institutional rehabilitation services, stroke rehabilitation can be offered outside the ambit of hospitals in India. Community-based Rehabilitation (CBR) is a strategy for rehabilitation and social inclusion of persons with disabilities⁵⁷. CBR is centred on meeting the basic needs, facilitating social participation and enhancing the quality of life of people with disabilities and their families using available local resources²⁷. Provision of CBR has been strongly recommended by the WHO in order to address rehabilitation barriers, especially in the LMICs²⁷.

I co-authored a systematic review on CBR for physical and mental disabilities in the LMICs⁶⁰. We identified two randomised-controlled trials for people affected by stroke. These were conducted in Thailand⁶¹ and China⁶² and investigated the provision of home-based rehabilitation on the quality of life and neurological functions of individuals affected by stroke. In the trial conducted by Chinchai et al (2010) in Thailand, the stroke survivors in the intervention group who received home-based rehabilitation for two months had a significant improvement on their quality of life scores during the two months of follow-up⁶¹. In the other trial, conducted by Yu et al (2008) in China, the stroke survivors in the intervention group received home-based rehabilitation for approximately five months. During follow-up, the stroke survivors in the intervention group showed greater improvement in their neurological functioning when compared to the participants in the control group⁶².

Two further non-randomised intervention studies were also identified in this review. A quasi-experimental study in China evaluated a community-based stroke prevention programme for mild stroke patients. This study documented a positive impact of the programme on patient knowledge and skills for managing their everyday living⁶³. A controlled before and after study carried out by Habibzadeh et al in Iran⁶⁴, showed a 32% improvement in the ADL score from baseline among the stroke survivors in the intervention group during the 45-day follow-up compared to the control group ($p < 0.001$). Thus, these studies provide supportive evidence that a community-based stroke rehabilitation programme could be a strategy to improve access and availability of stroke rehabilitation services in LMICs.

1.9.2 Educational Interventions for Stroke Rehabilitation

An educational intervention is a systematic, goal-oriented, structured process of imparting knowledge and developing skills to bring out a change in behaviour⁶⁵. Theoretically, educational interventions enhance comprehension of one's own problems and facilitate participation in their management⁶⁶. It is a process of enabling individuals to make informed decisions about their personal health-related behaviour⁶⁶. Educational interventions could assist stroke survivors and their families to access support services and to make informed decisions regarding their care⁶⁷. A recent systematic review of 21 trials with 2,289 stroke survivors and 1,290 carers showed evidence for improvement in patient and caregiver knowledge about stroke and aspects of patient satisfaction following the provision of information related to stroke⁶⁸. This review also suggested that educational interventions that include the active participation of the stroke survivors and a planned follow-up for reinforcing their learning will have a positive effect on their mood⁶⁸. In addition to this existing evidence, I have also undertaken a global comprehensive systematic review on educational

interventions for disabilities following acquired brain injury. Available evidence suggested that active, patient-centred, educational intervention reduces the extent of disability, enhances participation and improves quality of life in patients with ABI. A detailed description of this review is provided in Chapter 3

1.9.3 Self-management Strategy for Stroke Rehabilitation

Recovering from stroke is a long-term process that extends beyond hospital treatment and care. Therefore, a stroke survivor must actively participate in making important decisions that influence their long-term recovery⁶⁹. Stroke survivors might have to make several decisions in order to engage purposefully in their personal and social life, such as child-care, household management, work, leisure and engagement in social activities. Active involvement in rehabilitation programmes can help stroke patients gain knowledge and expertise in effective management of their disability following stroke⁷⁰. Thus, training the patients to self-manage their disability following stroke in their home / community could be a potential strategy to meet the rehabilitation needs of stroke patients. For example, educating the stroke survivor about the ways to appropriately position oneself on a bed or chair while sleeping and sitting could reduce spasticity and facilitate normal body movements.

Self-management programmes for chronic diseases are usually provided in the form of an educational intervention⁷¹. A self-management programme is a subset of any educational intervention focussed specifically on improving the self-efficacy of individuals with health needs⁷⁰. Self-management educational interventions are generally distinct from simple patient education programmes because they encourage the active participation of patients and their immediate carers in the management of their condition⁷¹

A systematic review by Warsi et al (2004) documented the benefits of a self-management education strategy for chronic conditions⁷². This review identified 71 trials related to self-management education and reported small to moderate effects of these methods for selected chronic conditions, such as diabetes, asthma and arthritis⁷². Self-management strategies could, theoretically, improve the ability of stroke survivors to exercise control over their actions to manage post-stroke disability⁷⁰, as these methods are expected to build self-efficacy in patients. This is positively associated with important post-stroke outcomes such as depression, ADL and quality of life⁶⁷. Another systematic meta-review that included 13 systematic reviews with 101 trials, documented high quality evidence for supported self-management intervention provided to the stroke survivors soon after their stroke⁷³. This meta-review showed improvements in basic and extended ADL, and a reduction in poor outcomes, such as dependency/death, among the stroke survivors⁷³.

1.9.4 Smartphone-enabled Carer-supported Educational Intervention for Self-management of Stroke-related Disabilities

Recent technological advancements have resulted in an increased use of smartphones for the provision of health-care services⁷⁴. The International Telecommunication Union estimated that globally six billion people were mobile phone users in the year 2011, equivalent to 87% of the world's population⁷⁵. It is estimated that more than half of all these mobile phone users will use a smartphone by 2018⁷⁶. At present, there are 1.91 billion smartphone users globally, with LMICs, especially India, China, Brazil and Russia, leading the market for smartphones⁷⁶. The report also stated that India will be the world's second largest market for smartphone sales and the number of smartphone users in India would exceed 200 million by 2016⁷⁶.

Smartphone-based self-management interventions are considered a viable option for reducing the substantial cost involved in managing chronic diseases⁷⁴. Smartphone-based health care interventions could act as a feasible tool for provision of reinforcement and advice to the patients for self-managing their health needs⁷⁷. Smartphone-based mHealth interventions enable instant communication between the patients and the healthcare providers or clinicians⁷⁸. Any updates or important information regarding therapy and care can be shared with a group of patient instantaneously⁷⁴. It also facilitates remote monitoring and follow-up of patients with chronic conditions⁷⁸, thus reducing the substantial costs involved in provision of continuous long-term care for the patients in their home^{74, 78}.

The management of chronic diseases using smartphone technology has been described in a recent systematic review⁷⁴. This review identified 83 healthcare applications for smartphones. Fifty-seven of these applications were for diagnosing diseases, 11 applications were related to medical and allied health student education and 15 applications were focussed on chronic disease management, such as diabetes, cardio-pulmonary problems, falls and hearing impairment⁷⁴. These disease management applications were designed for use by the patients⁷⁴. It was estimated that close to 500 million smartphone users will be using their phones for mHealth services by 2015⁷⁹.

Smartphone-enabled disease management interventions led by clinicians have also been shown to be beneficial for patients⁸⁰⁻⁸⁵. Smartphone applications used in stroke rehabilitation include one that was designed by Dr Droid to help therapists administer and track upper-limb exercises for stroke rehabilitation⁸² as well as a Think-FAST application that features stroke prevention information and a list of stroke unit locations in Australia⁸³. Recently Zhang et al

have developed the S3 application for provision of information related to medicine management and rehabilitation of stroke survivors. This application has a separate module for caregivers⁸⁴. The NICE guidelines for long-term stroke rehabilitation also recommend the use of smartphones for stroke patients with communication problems⁸⁶. However most of the current smartphone-based mHealth applications are available only in HICs.

1.10 Rationale for the Present Study

A chronic condition such as stroke requires uninterrupted therapeutic care and constant monitoring during the entire continuum of recovery⁵⁶. However, there are very few institutions that provide this kind of comprehensive healthcare and rehabilitation service⁵⁴. Most of these institutions provide either acute or post-acute stroke services that include early nursing and physiotherapy⁵⁴. Comprehensive multi-disciplinary stroke rehabilitation that looks at the long-term goals for stroke survivors like independent living and their active participation in family and social roles is not available in most of these hospitals²⁷. Also an active mechanism to follow-up those who received treatment for stroke in these hospitals is lacking²⁷. This situation warrants the development of an innovative strategy to educate stroke survivors and their families about stroke and the importance of therapeutic care during the continuum of recovery. This strategy could potentially empower them with adequate knowledge and help them take appropriate decisions during their recovery from stroke.

As mentioned in an earlier section, there is also an acute shortage of allied health professionals in India⁴⁹. Services like occupational therapy and speech therapy which are considered to be the first line of treatment during the post-acute rehabilitation phase are hardly available to the stroke survivors even in the existing facilities⁴⁹. Even if there is a

stroke rehabilitation team in the facility, it becomes very difficult for them to provide adequate information about recovery outside the hospital environment⁴⁶. This is especially because some of the equipment or assistive devices used within the facility like hoists, modified wheel chairs, splints, alpha beds and pressure relief cushions are neither available nor affordable outside the hospitals in India⁴⁸. The cost of stroke care is predominantly borne by the affected individual and their families. Hence, it becomes difficult for them to afford therapy services or assistive devices, outside these hospital facilities over a considerable period of time⁴⁸. Thus stroke care outside the hospital and stroke recovery in the community setting becomes impossible for most of the stroke survivors.

In the absence of any organised stroke care services, and with the limited resources available for rehabilitation, an eclectic approach to address the growing burden of stroke-related disability is needed in India⁵²⁻⁵³. This approach could be pivotal in integrating various strategies for rehabilitation (educational, community-based, smartphone-enabled, self/supported management,) mentioned in the previous section²⁷. It could also be useful in integrating some of the key aspects of various models for rehabilitation and have a ‘Biopsychosocial framework’ for the intervention, as proposed by the ICF⁶⁷. This eclectic approach to the development of an intervention could potentially ensure that all the components of disability are covered independently and also linked to each other within the intervention⁶⁷. In this case, this will be stroke, its impairments, activity limitations, participation restrictions, personal and the environmental factors. This kind of approach was envisaged to be a potential strategy to meet the substantial rehabilitation needs of stroke survivors in a LMIC such as India.

Stroke services in India are predominantly available at hospitals located in urban areas and are expensive⁴⁶. It is usually uni-disciplinary (physiotherapist-driven) and headed by a neurologist (Doctor)⁴⁶. Thus, it is crucial to develop an innovative and inclusive strategy that is different to the existing context for stroke care in India. It is imperative to develop an intervention that is multidisciplinary, widely available (even in rural areas), outside the hospitals (community-based), led by the stroke survivors and their family themselves (self/supported management) and affordable.

Optimistically looking at the technological developments in India to meet the needs of stroke survivors could be a key option. There are nearly 220 million smartphone users and about 150 smartphone brands in the market in India⁷⁶. These numbers are expected to increase over time⁷⁶. However, there is no information about the penetration level of smartphones in rural India. There is also very minimal information on the patterns of smartphone utilisation and its potential advantages and limitations in India.

India being the world's second leading market for smartphone sales and with a progressive penetration level of this smartphone technology widens the scope for development of a smartphone-enabled intervention for stroke⁷⁷. It also provides an opportunity to test the feasibility of using smartphone technology to help people with stroke-related disabilities in India. Evidence concerning the use of smartphones in chronic disease care in LMICs is now emerging and the use of smartphones in interventions to combat diseases like diabetes, hypertension and cardio-vascular diseases is being progressively investigated⁷⁴. Available evidence suggests that, adoption of this strategy could possibly reduce the barriers to access

and availability of stroke rehabilitation services⁷⁸⁻⁷⁹. It could also aid in efficient and sustained monitoring of patient progress throughout the continuum of care⁷⁸⁻⁷⁹.

Thus, this PhD research project seeks to develop and evaluate an integrated eclectic intervention that combines the principles of CBR, ICF, mHealth and also the needs of the stroke survivors. The intervention will be educational in nature and its content will be digitized and presented in an audio-visual format. Given this integrated approach to intervention development, evidence from the systematic or non-systematic review of literature alone will not be sufficient to inform the content of the intervention. An empirical exploration of this approach will provide valuable information for the development of an evidence-based intervention, tailored to the needs of the stroke survivors in India. Hence it was decided that a mixed-methods approach will be used to develop the intervention and evaluate its feasibility and acceptability.

Mixed methods approach provides multiple views and perspectives about the research question⁸⁸. It helps the investigator to contextualise these perspectives to gain a complete understanding of the problems and develop the best content for the intervention. This approach is expected to improve the comprehensiveness of the content, making it more useful to the stroke survivors and also very relevant to the context⁸⁸. Thus an eclectic biopsychosocial framework and a mixed methods approach for developing and evaluating the intervention was considered and conceptualised. This kind of approach was envisaged to provide pragmatic solutions required to address the growing burden of stroke disability in India and in other similar resource-constrained settings.

According to a recommendation by the Medical Research Council (MRC), the development and evaluation of a complex intervention requires a phased approach⁸⁸, so as to allow researchers to clearly define the various phases of the research process⁸⁸. Thus, the purpose of this PhD research study was, (conforming to the MRC framework) to systematically develop an educational intervention for management of physical disability following stroke and evaluate the feasibility and acceptability of delivering the intervention using Smartphones and with caregiver support.

This research will provide an opportunity to develop a patient-centred, smartphone-enabled, educational intervention for management of post-stroke disability that is relevant to the context of the LMICs. Findings from this study will also provide valuable information about the resources required to deliver such interventions in resource-constrained settings.

1.11 The Study Setting

This study was carried out in Chennai, the capital city of Tamilnadu, located in south India (Figure 1.5). Chennai is the 5th fifth largest and fourth most populous metropolitan city of India, with approximately 6.5 million people⁸⁹. It is a leading commercial centre and a cultural hub for south India⁹⁰. It ranks as the 36th largest urban area in the world⁹¹⁻⁹². Nearly 18.5% of the population in Chennai are slum dwellers and 51% of the households in Chennai live in rented houses^{89, 91-92}. The majority of the population in Chennai is Tamil, which is also the primary language spoken⁸⁹.

Figure 1.5 Map of India showing the location of Tamilnadu and Chennai.



Chennai has been termed India's health capital⁹¹. The city has world class medical facilities owned by both the government and the private sector⁹¹. The city has more than 12,500 beds in the government hospitals and approximately 8,400 beds in private hospitals⁹². Significant proportion of people living in Chennai will fall under middle socio-economic status group⁸⁹. However, only 50% of these beds are used by the city's population. People from other states and countries share the other half ⁹². This is because, health care in Chennai is usually available at a reasonable price compared to other cities and states in India. Additionally, there are a couple of government tertiary hospitals and few private hospitals and hospitals established by NGOs that cater to services for stroke patients in Chennai.

There are several reasons for choosing Chennai as the study location. Firstly, majority of people living in Chennai belong to middle class family (middle socio-economic status group)⁸⁹. Conducting the research study in Chennai would help us in generalising the findings of the research study to population which is considered to be a representative sample of the

country (>50% Middle class population). Secondly, the city being India's health capital attracts many people with stroke for treatment and care and it would be possible to identify and recruit the proposed number of study participants without significant delays. Thirdly, the cost of treatment and care is relatively reasonable when compared to other cities in India. Given these advantages, it was decided that Chennai could be a feasible location to conduct this research study. People in India speak many different languages and it will not be feasible to validate the intervention in all these languages. Since this PhD research was designed as a 'proof of concept' study, I chose only one language (i.e. Tamil) which is the vernacular language of people living in Chennai.

There was no listing of the details of stroke patients in the existing registries and hence it was not possible to initiate this research study from the registries. Conducting a community-based participant selection (surveys) can also be resource intensive and time consuming within the scope of this PhD; hence I was advised by my PhD supervisors to identify participants from hospitals for this research study. This strategy was considered to be beneficial in terms of obtaining more clinical details about the treatment received by these stroke survivors and their treatment experience. However, the contact details of the stroke survivors who approached these hospitals for their treatment was the only primary information that was required from the hospitals.

The initial plan was to include as many study sites or centres as possible from various parts of India for conducting the research study. The investigator (SK) first enlisted several hospitals from various states within India for participant recruitment. The list included government hospitals, private hospitals and hospitals led by NGOs (28 hospitals in total). With the

assistance from my supervisor and other known contacts, all the hospitals enlisted were formally contacted.

A formal letter from the supervisor introducing the investigator and the research study was shared initially via email with the key contact person in these hospitals (e.g. Head of the department, Director of research, Vice chancellor of the university, Medical superintendent, Professors, Registrars and Stroke consultants etc.). Following this, the investigator obtained permission to meet the key contact person, handed over the requisition letter and personally explained about the study. This process took a considerable amount of time since most of the contact persons did not respond to the emails, some did not provide permission to meet, some were very busy and some were not available. There have been many instances where the investigator had to wait the whole day to meet a contact person and yet was not successful. There might be various valid reasons behind this and discussing about it would be outside the scope of this PhD.

From the 28 hospitals initially contacted, only one hospital located in Chennai, Tamilnadu was willing to provide permission to conduct this study. This hospital is an old renowned hospital for treatment of neurological disorders. The hospital was called the Voluntary Health Services (VHS) hospital and the department was called The T.S. Srinivasan Institute of Neurological Sciences (TINS). The TINS department was equipped with 3-4 neurologists and 3-5 Medical officers with expertise in neurology. It provides assessment and treatment services for various kinds of neurological illnesses including stroke. It also had additional services like clinical psychology, therapy and rehabilitation both on an in-patient and an out-patient basis.

Whenever a stroke patient is brought to this hospital, they will be provided treatment at intensive care unit of VHS. The medical officer of that unit will refer the patient to TINS or Neuro-surgery based on his discretion. Once the patient is referred to TINS, they will be assessed by the neurologist from TINS and then the decision will be taken about their treatment plan (whether they will be treated or out-patients or in-patients) and it will be implemented. If the stroke survivor has additional comorbidities like renal problems, bowel and bladder issues and other medical conditions, they will be referred to the concerned department within the hospital but most of the specialist doctors will be requesting the patient to fix up an appointment at their own private clinic outside the hospital. This is because; the specialist would be usually busy with patient load from their department and would not have time for accepting referrals from other departments. In these instances, the patients were allowed to get appointment and consult these specialists in their clinics. However, the cost of referral appointments, investigations, medicines, therapy, food and transport has to be borne by the patients and their family.

The cost of an out-patient appointment was around Rs 500 (5 GBP) excluding prescribed medicines which will mostly be available at private pharmacies where people have to pay from their pocket. There was no diagnostic facility like a CT-Scan or MRI within the hospital premises. In order to have the CT or MRI Scan, the patients are transferred to a diagnostic centre outside this hospital and they pay for these services too.

The TINS department has an in-patient therapy unit with 12 beds (6 for females and 6 for males) with nursing, physiotherapy and psychology services. Occupational therapy services, speech therapy services, orthotic services are neither available in TINS or VHS. The cost of in-patient therapy service was INR 2000 for a week (excluding medicines and diagnostic

services). It will usually be a mix of patients with different kinds of neurological problems in the in-patient unit (Stroke, Multiple sclerosis, Epilepsy, Spinal cord injury, dementia etc.). There was no community-based follow-up service for the patients treated at TINS or VHS. The VHS hospital also has a neuro-surgery department which also looks at similar kinds of patients but with intense needs for neuro-surgical interventions. However it runs as a separate department with very limited functional or administrative relations with TINS.

1.12 Overall Aim and Strategy for the Study

The aim of this study was to develop and evaluate a Smartphone-enabled, carer-supported education programme for stroke survivors in India.

1.13 Phases of the Formative Research Study

This study was conducted in three phases:

- 1) Development of the intervention;
- 2) Pre-testing of the intervention and stakeholder consultation;
- 3) Piloting of the intervention, including assessment of feasibility and acceptability.

1.14 Specific Objectives of the Research Study

The specific objectives of each phase were as follows:

1.14.1. Phase 1: Development of the Intervention

1. Review the incidence and prevalence of stroke in India.
2. Assess the existing evidence for educational interventions used in the rehabilitation of stroke survivors.
3. Explore the experiences of stroke survivors and their caregivers in accessing

stroke rehabilitation services in India.

4. Assess the rehabilitation needs of stroke patients and their caregivers, following a stroke and after discharge from hospital.
5. Assess the experience and comfort of stroke survivors and their caregivers in using Smartphone technology.
6. Investigate the barriers and facilitators to the uptake of rehabilitation by stroke survivors following hospital discharge.
7. Consult with key stakeholders to decide on the best content for the intervention.
8. To develop and digitise the content of the intervention and transfer it onto the Smartphone.

1.14.2. Phase 2: Field-testing of the Intervention

9. Assess the ability of stroke survivors and their carers to operate a Smartphone for accessing the intervention.
10. Observe the participants while they use the provisional Smartphone-enabled intervention in order to determine the training needs and operational requirements related to the intervention.
11. Consult with key stakeholders to refine and finalise the intervention.

1.14.3. Phase 3: Piloting of the Intervention and Assessment of Feasibility and Acceptability

12. Determine the feasibility of delivering the Smartphone-enabled, carer- supported educational intervention for stroke survivors
13. Determine the acceptability of the intervention among stroke survivors and their primary caregivers

Chapter 2

Methods

Preamble

This study is the first ever attempt at developing a Smartphone application for post-stroke rehabilitation in India. As mentioned before, a systematic approach was followed to develop a smartphone-based educational intervention and to evaluate the feasibility and acceptability of the same in an Indian context.

This research study was conducted in three phases with distinct objectives for each phase. The results of the preceding phase helped develop and inform the subsequent phase. Detailed methodology adopted for the study has been published in BMJ Innovations 2015. This paper is enclosed as chapter - 2 and it describes each step followed in the study in greater detail.

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SECTION A – Student Details

Student	SURESHKUMAR KAMALAKANNAN
Principal Supervisor	PROF GVS MURTHY
Thesis Title	Development and evaluation of a Smartphone-enabled Carer-supported Educational intervention for management of disabilities following stroke in India

If the Research Paper has previously been published please complete Section B, if not please move to Section C

SECTION B – Paper already published

Where was the work published?	BMJ Innovations		
When was the work published?	July 2015		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion	Not Applicable		
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Where is the work intended to be published?	Not Applicable
Please list the paper's authors in the intended authorship order:	1. K Sureshkumar, 2. GVS Murthy, 3. Sanjay Kinra, 4. Shifalika Goenka, 5. Hannah Kuper
Stage of publication	Choose an item. <u>ALREADY PUBLISHED</u>

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)

I conceived and designed the study under the guidance of my supervisors Prof GVS Murthy and Dr Hannah Kuper. I also wrote the first draft of the manuscript and prepared subsequent revisions with consideration of comments from my supervisors and other co-authors.

Student Signature: _____

Date: 7/8/2015

Supervisor Signature: _____

Date: 7/7/2015



ORIGINAL ARTICLE

Development and evaluation of a Smartphone-enabled, caregiver-supported educational intervention for management of physical disabilities following stroke in India: protocol for a formative research study

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ABSTRACT

The incidence and prevalence of stroke in India has reached epidemic proportions. The growing magnitude of disability in patients with stroke in India poses a major public health challenge.

Given the nature of the condition, affected individuals often become disabled with profound effects on their quality of life. The availability of rehabilitation services for people with disabilities is inadequate in India. Rehabilitation services are usually offered by private hospitals located in urban areas and many stroke survivors, especially those who are poor or live in rural areas, cannot afford to pay for, or do not have access to, such services. Thus, identification of cost-effective ways to rehabilitate people with stroke-related disability is an important challenge. Educational interventions in stroke rehabilitation can assist stroke survivors to make informed decisions regarding their on-going treatment and to self-manage their condition with support from their caregivers. Although educational interventions have been shown to improve patient knowledge for self-management of stroke, an optimal format for the intervention has not as yet been established, particularly in low- and middle-income countries. This formative research study aims to systematically develop an educational intervention for management of post-stroke disability for stroke survivors in India, and evaluate the feasibility and acceptability of delivering the intervention using Smartphones and with caregiver support. The research study will be conducted in Chennai, India, and will be

organised in three different phases. *Phase 1:* Development of the intervention. *Phase 2:* Field testing and finalising the intervention. *Phase 3:* Piloting of the intervention and assessment of feasibility and acceptability. A mixed-methods approach will be used to develop and evaluate the intervention. If successful, it will help realise the potential of using Smartphone-enabled, carer-supported educational intervention to bridge the gaps in service access for rehabilitation of individuals with stroke-related disability in India. The proposed research will also provide valuable information for clinicians and policymakers.

BACKGROUND

Stroke is a major global public health problem. According to the Global Burden of Disease (GBD) study in 2010, stroke is the second leading cause of death worldwide.¹ A person experiences a stroke when a blood clot blocks a blood vessel in the brain or a vessel that supplies it, or when there is bleeding in the brain. The interruption of blood supply to the brain reduces the supply of oxygen and nutrients to it, causing injury and death of brain tissue.² This brain damage may subsequently result in long-term disability or death of the affected individual.²

Stroke is associated with a wide variety of sensory-motor, cognitive-perceptual and behavioural impairments.³ The effects of stroke will depend on the site

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of the brain lesion and severity of brain damage.⁴ In addition to the primary impairments following a stroke, secondary complications of stroke can also hamper the recovery process.⁵ The prognosis in stroke depends on the degree of primary impairments and secondary complications.⁴

Disability is an umbrella term, covering impairments, activity limitations and participation restrictions.⁶ Impairment following stroke may present as physical, mental or cognitive. Stroke impairment might limit the ability of the stroke survivor to independently perform his or her daily living activities (eg, difficulties in walking or communicating).⁶ Consequently, it might also restrict effective participation of the stroke survivor in his/her family and social roles.⁷ Disability following stroke depends on the degree of impairment (physical, mental, cognitive) as well as the personal and contextual environment of the affected individual. Most often, stroke survivors become disabled with profound effect on their quality of life.⁸

The impact of disability following a stroke also affects the family of the stroke survivor.⁹ Adapting to the new role of a carer and adjusting to the sudden impact of stroke can be highly stressful for family members.¹⁰ The demand on caregivers increases tremendously, especially if the stroke survivor experiences severe disability.¹¹ The rehabilitation needs of stroke survivors and their family will vary extensively based on the degree of impairment and the context in which they experience a stroke (eg, accessibility to stroke services, family support, etc).^{7,9-12}

REHABILITATION NEEDS OF STROKE SURVIVORS IN INDIA

Evidence from a literature review suggests that India is experiencing a silent epidemic of stroke.¹³ Prevalence rate of stroke in India is estimated to range from 84 to 262/100 000 in rural areas and 334 to 424/100 000 in urban areas. The incidence rate is 119–145/100 000 based on recent population based studies.¹⁴ The incidence and prevalence of stroke was observed to be higher in India, compared to the incidence and prevalence of stroke in high-income countries (HICs).¹³ Unlike HICs, there is a dearth of information about the rehabilitation needs of people with disabilities following stroke in India.¹⁴ People with disabilities in general encounter tremendous environmental barriers in accessing rehabilitation services in India.¹⁵ Lack of policy initiatives for rehabilitation, inadequate rehabilitation resources and health professionals, lack of an accessible environment and stigma are some of the major barriers that persons with disability experience in India.¹⁶ Taking into account the disability after stroke and the existing environmental barriers to rehabilitation, the needs of stroke survivors in India are expected to be substantial and diverse.

REHABILITATION SERVICES IN INDIA

Rehabilitation services in India are usually hospital-based and driven predominately by physiotherapists. Therapy inputs from other health professionals, such as occupational therapists and speech therapists, are hardly available to patients with stroke.¹⁷ A recent study undertaken by the Public Health Foundation of India (PHFI) for the Ministry of Health and Family Welfare (MoHFW) has indicated a supply-demand gap of about 6 500 000 allied health professionals in India.¹⁸ Even the information needs of patients with stroke and their primary caregivers to self-manage their problems following stroke remain largely unfulfilled.⁷ Provision of rehabilitation services in India are usually limited to specialised hospitals located in urban areas, and many people, especially those who are poor or who live in rural areas cannot afford to pay for, or have limited access to, such services.¹⁸ When patients and caregivers travel long distances to obtain rehabilitation services, there is a huge financial implication and opportunity cost involved in accessing these services.⁷ Although the number of private rehabilitation facilities in India has increased, these are only accessed by a minuscule proportion of the country's vast population.¹⁹ Owing to these reasons, most people with disabilities following stroke do not have access to rehabilitation services in India.²⁰ The existing barriers to rehabilitation suggest that the rehabilitation needs of the stroke survivors in India remain largely unmet.

Given the context, it is imperative that stroke survivors and their caregivers are educated about stroke and the ways to manage post-stroke disability on their own. Educational intervention could assist stroke survivors and their families to access support services and to make informed decisions regarding their care.^{21,22} Educational interventions were found to improve patients' and carers' knowledge on the self-management of stroke.²³

A chronic condition such as stroke requires uninterrupted therapeutic care and constant monitoring during the entire continuum of recovery.²³ In the absence of any organised stroke care services and with the limited resources for rehabilitation, a Smartphone-enabled educational intervention for management of disability could be a strategy to meet the substantial rehabilitation needs of stroke survivors in India.²⁴ The evidence concerning the use of Smartphones in chronic disease care in India is finally emerging and the use of Smartphones in interventions to combat diseases such as diabetes, hypertension and cardiovascular diseases, is progressively being investigated.²⁵ In some HICs, Smartphones are used to create awareness about the warning signs of stroke²⁶ and also to aid rehabilitation of language and communication impairments following stroke.²⁷ Adoption of this strategy could possibly reduce the barriers to access and availability of stroke rehabilitation services. It could also aid in efficient and sustained monitoring

of patient progress throughout the continuum of care. Thus, this study seeks to develop and evaluate a Smartphone-enabled carer-supported educational intervention for management of physical disabilities following stroke in India.

OVERALL AIM AND STRATEGY OF THE STUDY

The aim of this study is to develop and evaluate a Smartphone-enabled, carer-supported education programme for stroke survivors in India. The purpose of this formative research is to systematically (conforming to the MRC framework²⁸) develop an educational intervention for management of post-stroke disability for stroke survivors in India, and evaluate the feasibility and acceptability of delivering the intervention using Smartphones and with caregiver support.

This study will be conducted in three phases: (1) development of the intervention; (2) pre-testing of the intervention and stakeholder consultation; and (3) piloting of the intervention, and assessment of feasibility and acceptability. Processes and activities involved in each phase of the research study are explained using a flow chart in figure 1, and are described in detail below.

This study will apply mixed research methods in order to collect more comprehensive evidence and have a deeper understanding of the research problem. Mixed methods research encourages the use of multiple worldviews, and is a practical and natural approach to research pertaining to development of a complex intervention.²⁹ It is premised on the idea that the use of quantitative and qualitative approaches in combination provides a better understanding of research problems than either approach alone.³⁰

PROPOSED STUDY DESIGN

Methods: phase 1: Development of the intervention

The overall objective of this phase is to develop a Smartphone-enabled, carer-supported education

intervention for stroke survivors to manage their post-stroke disability. Research questions that will be answered in this phase along with the methods are detailed in table 1. At the end of phase I, a provisional Smartphone-enabled educational intervention for management of stroke-related disability will be developed for field testing and refinement. This provisional intervention will encompass the rehabilitation needs of patients with stroke and their caregivers identified in this formative phase.

Detailed methods for phase 1

Study setting

Participants will be selected from hospitals within Chennai that provide treatment and rehabilitation services for stroke survivors, and that are willing to recruit participants for this phase. Hospitals that could be potential recruitment sites for this phase will be identified and contacted, and permission will be obtained. Chennai, with a population of over 9 million, is the capital city of the Indian state of Tamil Nadu. It is the biggest industrial and commercial centre in South India, and a major cultural, economic and educational centre in the country.

Participant inclusion criteria:

1. Participants with a recently diagnosed stroke (within the previous 6 weeks) as defined by the WHO;³¹
2. Aged ≥ 18 years;
3. Presenting with minor and moderate stroke (ie, scoring 1–15, according to the National Institute of Health (NIH) stroke scale);^{32–34}
4. Discharged from the hospitals (recruitment sites);
5. Residing at home with a primary caregiver.

Exclusion criteria:

1. Stroke survivors with severe communication problems identified using the NIH stroke scale;^{32–34}
2. Stroke survivors who cannot provide consent autonomously;
3. Those presenting with severe stroke (ie, scoring >15 , according to the NIH stroke scale).^{32–34}

Survey of study participants using structured questionnaires

From the participants who meet the inclusion criteria, a purposive sample will be selected for the questionnaire survey.

- *Stroke survivors:* 50 participants admitted to hospital and then discharged within the previous 6 weeks.
- *Primary caregivers of the stroke survivors:* 50 participants.

This phase will have a pragmatic approach to participant recruitment. The initial recruitment will include all eligible participants. In the later stage, recruitment will be more focused on the potential subgroups of participants stratified by their age, gender and severity, for gaining a better understanding of their specific experiences and rehabilitation needs.

The purpose of this survey is to identify the various kinds of rehabilitation needs of stroke survivors, and

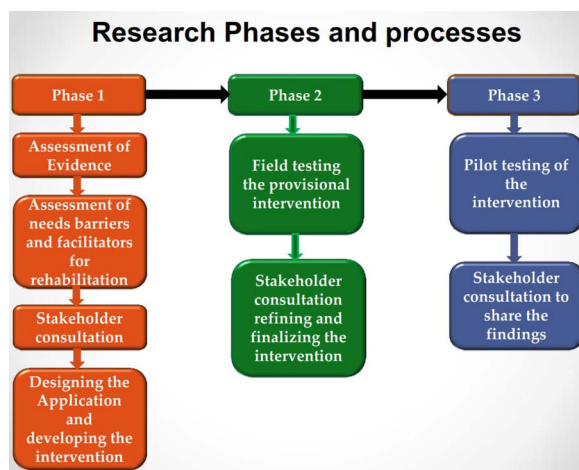


Figure 1 Flow chart of the processes and activities of the research phases.

mHEALTH AND WEARABLE HEALTH TECHNOLOGIES

Table 1 Objectives, research questions and methods for phase I

Objectives	Questions	Methods
Explore the experience of the stroke survivors and their caregivers in accessing stroke rehabilitation services	<ul style="list-style-type: none"> ▶ What impact does a stroke cause in the life of a stroke survivor, and his/her family and caregiver? ▶ How does an individual affected by stroke and his/her family organise themselves to manage the effects of stroke? ▶ What measures will stroke survivors and their caregivers take in order to manage disability following stroke? ▶ What is the general understanding of the stroke survivor and his/her caregiver about stroke rehabilitation? ▶ What kind of stroke rehabilitation services are generally available to stroke survivors, from where and from whom? ▶ At what phase of recovery are these rehabilitation services available to stroke survivors? ▶ How do stroke survivors usually access stroke rehabilitation services? ▶ What is the general perception of stroke survivors and their caregivers on the quality of available rehabilitation services? ▶ What are the difficulties faced by stroke survivors in accessing rehabilitation services? ▶ What is the cost of obtaining stroke rehabilitation services and what is the impact of this increased expenditure on the family? 	Survey using structured questionnaire and in-depth interviews with stroke survivors and their caregivers
Assess the information needs of patients with stroke and their carers	<ul style="list-style-type: none"> ▶ What information do stroke survivors and the caregivers need to manage disability following a stroke? ▶ What kind of information is available to them, from where and from whom? ▶ At what point of time or phase of recovery (acute, post-acute, rehab, long-term care), is this information available to them? ▶ What is the quality of available information (regarding correctness, relevance, reliability and understandability)? 	Survey using structured questionnaire and in-depth interviews with stroke survivors and their caregivers
Assess the rehabilitation needs of patients with stroke	<ul style="list-style-type: none"> ▶ What are the various kinds of disability experienced by stroke survivors following stroke? ▶ What are the various rehabilitation needs (physical, psychological, social) of stroke survivors and their caregivers? ▶ What kinds of rehabilitation services are required to address the needs of stroke survivors and their caregivers? ▶ What kind of rehabilitation services would enable stroke survivors to be functionally independent following stroke? 	Survey using structured questionnaire and in-depth interviews with stroke survivors and their caregivers
Assess the barriers and facilitators for rehabilitation of stroke survivors	<ul style="list-style-type: none"> ▶ What are the present policies and programmes for rehabilitation of persons with disabilities especially following stroke? ▶ How are these rehabilitation policies and programmes implemented? Are there adequate resources (human resources, material and financial resources) for rehabilitation of stroke survivors? ▶ How are these rehabilitation services delivered to stroke survivors? ▶ What are the constraints in providing rehabilitation services to stroke survivors? ▶ What can be done to address these constraints? ▶ What are the facilitating factors for provision of rehabilitation services for stroke survivors? 	In-depth interviews with health professionals providing stroke rehabilitation services in hospitals
Assess the experience and comfort of the stroke survivors and their caregivers in using Smartphone technology	<ul style="list-style-type: none"> ▶ Has the stroke survivor and/or caregiver ever used a Smartphone? ▶ What was their experience in using Smartphone technology? ▶ How long and for what purpose were they using the Smartphone? ▶ What abilities are essential/required to use a Smartphone comfortably? ▶ Will a Smartphone-enabled carer-supported education programme be useful for stroke survivors? 	In-depth interviews with stroke survivors and their caregivers

Continued

Table 1 Continued

Objectives	Questions	Methods
Recommendations for action	<ul style="list-style-type: none"> ▶ What are the advantages and disadvantages of such interventions? ▶ What are the potential rehabilitation strategies to facilitate functioning, participation and independent living among stroke survivors? ▶ What are the resources required to implement the rehabilitation strategy? ▶ Is the strategy feasible and sustainable? ▶ How can the proposed rehabilitation strategy be implemented and made sustainable? ▶ What could be the potential barriers/problems for implementation? What are the possible solutions to address the implementation barriers? 	In-depth interviews with health professionals providing stroke rehabilitation services in hospitals

the barriers and facilitators encountered by stroke survivors to access stroke rehabilitation services.

Study participants—in-depth interviews

From the participants selected for the survey, a sub-sample will be selected for in-depth interviews, including:

- ▶ 10–15 stroke survivors;
- ▶ 10–15 primary caregivers of stroke survivors.

The purpose of the in-depth interviews is to gain detailed understanding of the experiences of the stroke survivors in relation to accessing stroke rehabilitation services and their rehabilitation needs following stroke. Participants will be asked about their experiences of accessing stroke rehabilitation services, their rehabilitation needs, and about the barriers and facilitators to rehabilitation in various domains of their daily life, such as self-care, mobility and home-management; and leisure, social and vocational activities.

In addition, a purposefully selected sample of 8–10 health professionals from different rehabilitation disciplines (eg, rehabilitation medicine, neurology, physiotherapy, occupational therapy, speech therapy) will be selected and interviewed in depth. The purpose is to understand the perspective of the health professionals about provision of stroke rehabilitation services. This will include their understanding about the barriers and facilitators to accessing stroke rehabilitation services, their knowledge about the existing Smartphone-based health interventions, and their attitudes and opinions about the use of a Smartphone enabled, care-supported education programme for domiciliary stroke rehabilitation.

The in-depth interview process will end when the collection of new qualitative information does not shed any further light on the issue under investigation (saturation point). If the interviews with the proposed number of participants do not reach a saturation point, additional interviews will be conducted until saturation.

An investigator will administer the questionnaire verbally and will be conducting the interviews in

English or Tamil, whichever is suitable for the respondents. The interviews for stroke survivors and their primary caregivers will take place at their homes. For the health professionals, the in-depth interviews will take place at their respective hospitals. Interviews and discussions will be conducted in a secluded area so that participants' privacy and confidentiality is assured. All the interviews will be tape recorded.

Study tools

Separate questionnaires and topic guides will be developed for stroke survivors, their primary caregivers and health professionals, and pilot-tested before starting the study. The tools will be revised accordingly after the pilot-testing. The questionnaire will predominantly include close-ended questions with scaled responses. The questionnaire will be developed based on the WHO-Disability Assessment Schedule (WHODAS),³⁵ and also from tools used in previous studies.³⁶ The in-depth interviews will have specific topic guides with open-ended questions and prompts.

Informed written consent

All eligible participants will be informed about the study, and written consent will be obtained from those who are willing to participate. Stroke survivors who are discharged from the hospital (within a 6-week window prior to the study) and their caregivers will be identified using the hospital discharge records and contacted over the phone. The purpose and processes of the study will be explained to the participants and consent will be obtained from potential participants in person.

Analysis

Quantitative analysis of questionnaire survey data

Investigators will use STATA V.13.0 (StataCorp 2013. Stata Statistical Software: Release 13. College Station, Texas: StataCorp LP, USA) for analysis of data from the questionnaire schedule. Data will be double entered and compared, to detect and correct any errors that might have occurred during the data entry. The questionnaire schedule will have specific domains

of interest. The descriptive frequencies, and 95% CI for each of these domains will be calculated.

Qualitative analysis of in-depth interviews

Transcribing qualitative data

Transcribing will be carried out to produce a written version of the interview. It is a full 'script' of the interview.³⁰ Hand written interview notes will be documented in detail on the same day in order to avoid losing information. Tape-recorded information from the in-depth interviews of study participants will be fully transcribed verbatim within 3–5 days after the interviews. Consideration will be given to how certain things were communicated, and to the context, feelings and meanings, while transcribing. Punctuation marks and techniques such as underlining, marking with symbols, using upper case lettering, underlining and bolding during the transcribing process, will be used during analysis. Each transcribed interview will be reviewed as soon as possible and before the next interview in order to incorporate any interesting findings into the next interview, and to explore them further. Investigators will use the framework approach to carry out the qualitative analysis. The transcribed data will be analysed using the following steps:

- A. Familiarisation with the data;
- B. Identifying a thematic framework;
- C. Indexing;
- D. Charting;
- E. Mapping and interpretation.

Results of the analysis will inform the design and development of the intervention. The overall framework of the intervention package will be finalised after the formative phase.

Triangulation of information—stakeholder participatory workshops

Findings from the systematic reviews and the formative work (phase I) will be shared during a participatory consultation workshop with 8–10 key stakeholders (stroke survivors, primary caregivers, health professionals, and disability and rehabilitation experts) who will be selected for the study. Such workshops will be conducted at the end of each phase of the research (3-workshops in total). The purpose of the workshop is to facilitate triangulation of the information obtained from each phase and to reach a decision on the best content for the intervention. The participatory consultation workshops will be organised to bring in the key stakeholders together to seek their opinions, extract their knowledge and to decide on the best content for the intervention in a collaborative and creative environment.

Integrating the content of the education intervention with the Smartphone

The educational intervention developed during the formative phase of the research will be transformed into a Smartphone-enabled intervention. This process

will enable stroke survivors and their caregivers to use a Smartphone to access the intervention. The steps involved in developing the Smartphone enabled education programme are as follows

1. The content of the stroke education intervention (eg, positioning techniques, pressure relief procedures, self-care tasks, functional ambulation and exercises) will be converted into an animated or an illustrated (using patient demonstration) video version.
2. The digitised animated/video version of the stroke education intervention will be uploaded onto a Smartphone using an appropriate (Android/Windows) application platform. This will enable the participants to access the educational intervention package using the Smartphone. If there are any operation problems in uploading or technical issues with the Smartphone application, the digitised video clips will be transferred onto a specific folder that contains videos in the Smartphone.
3. Once the stroke education intervention is uploaded onto the Smartphone, the Smartphone-enabled educational intervention will be ready for use by the participants.

PHASE II METHODS

Phase II: Pre-testing of the intervention and stakeholder consultation

Field testing of the intervention

The provisional Smartphone-enabled intervention package will be field tested with a subsample of 30 adult stroke survivors and their caregivers. For this, a subsample of stroke survivors and their caregivers will be purposively identified from phase 1 survey respondents, excluding those who were part of the in-depth interview process. The Smartphone loaded with the intervention will be provided to the participants to be used at home for 2 weeks. Primary caregivers of stroke survivors selected for this phase will be asked to support the stroke survivors in accessing the intervention from the Smartphone.

Direct observation during field-testing

Utilisation of the Smartphone-enabled intervention and the support provided by the caregivers to the stroke survivors will be assessed by an Occupational Therapist (SK) using direct observation techniques during this phase. The main purpose of using a direct observation technique in this phase is to triangulate and affirm the information provided by the participants during phase 1. Some of the key issues that will be assessed during the direct observation include:

- A. Relevance and comprehensibility of the intervention;
- B. Operational difficulties of the participants in using the Smartphone;
- C. User-friendliness of the intervention;
- D. Technical issues in the Smartphone;
- E. Training needs in order to access the intervention from the Smartphone.

An observation checklist will be developed and used to assess these key issues during field-testing. The

outcome of the field-testing will inform the development of a finalised version of a completely illustrated, pictorial training manual (user-friendly even for participants with low literacy level) explaining the operation of the Smartphone to access the intervention.

Stakeholder consultation: refinement of the educational intervention

The outcomes of the field testing phase will be shared with the key stakeholders for their feedback and recommendations during the second participatory consultation workshop. The objective of this workshop is to consult with stakeholders about the feasibility of the intervention, receive feedback and refine the intervention, as recommended by the stakeholders. The consultation workshop will be a participatory process as described above. Recommendations from the stakeholder consultations will be used to refine the intervention package for the pilot phase.

Phase III: Piloting of the intervention and assessment of feasibility and acceptability

The objective of this pilot phase is to implement the intervention, and evaluate the feasibility and acceptability of the intervention. This phase will be carried out as a pilot study, which will provide useful information to plan a large scale RCT of the intervention in the future.

PHASE III: METHODS

Participants and eligibility criteria

Participants with a primary diagnosis of stroke will be recruited from VHS hospital in Chennai, India.

The inclusion criteria will be:

- ▶ Adults ≥ 18 years;
- ▶ Recent diagnosis of first ever stroke—as defined by the WHO³¹ within 3–6 weeks prior to the recruitment;
- ▶ Severity of stroke, mild and moderate (score 1–15, according to the NIH stroke scale);^{32–34}
- ▶ Stroke survivor medically stable (reaching a point in medical treatment where life-threatening problems following stroke have been brought under control);
- ▶ Post-stroke functional status of the stroke survivor: requiring assistance of one person to perform basic activities of daily living including transfers, self-care and mobility;
- ▶ Stroke survivor residing with a primary caregiver (family member) at home.

The exclusion criteria will be

- ▶ Participants with NIH score > 15 ;
- ▶ Severe cognitive difficulties (NIH stroke scale components for cognition);³⁴
- ▶ Severe communication problem;
- ▶ Severe comorbidities (severe psychiatric illness, hearing loss, vision loss);
- ▶ Stroke survivor functionally dependent due to pre-existing conditions;
- ▶ Stroke survivor who does not have a primary caregiver;

- ▶ Stroke survivors who are unwilling/unable to adhere to the study protocol;
- ▶ Participants who do not qualify the training requirements (operation of Smartphone).

Eligibility assessment using NIH stroke scale will be conducted by the investigator to identify participants to be recruited for this pilot study.

Participant recruitment for the pilot study

Participants for the pilot study will be recruited after their hospital discharge. Information about participants who are discharged from the hospital (in the past 3–6 weeks) will be retrieved from hospital records. An eligibility assessment will be completed within 2 weeks after identification of the participant from the hospital records. Participants identified for the piloting will be identified and contacted by phone. They will be informed about the purpose and processes of the study. If a participant is interested, written informed consent from the participant will be obtained in person. Consent procedures will be completed at the participant's home.

Participants for the pilot study

A total of 30–40 participants will be recruited from VHS hospital in Chennai for the pilot phase. The admission rate of stroke survivors in this hospital is 3–4/weeks. Given the hospital admission rate, it will take 4–5 months to recruit 30–40 participants who will meet the eligibility criteria for this phase.

Intervention procedure

The Smartphone uploaded with the intervention will be provided to the participants and we will show the stroke survivors and their caregivers how to use the Smartphone-enabled intervention. If the stroke survivor requires assistance, their caregivers will be encouraged to support them in using the intervention. The participants will be introduced to the intervention during initial home-visit. A structured training session for the stroke survivors and their caregivers on using the Smartphone-enabled intervention will be provided. The structured training will include:

- A. Introduction to the Smartphone-enabled intervention.
- B. Accessing the educational intervention package using the smart-phone application.

The finalised manual for Smartphone operation to access the intervention will be used during this training. A copy of the finalised Smartphone operation manual will be provided to the study participants for use at home. An occupational therapist (SK) will also assess whether the participants are able to use the Smartphone application (hands-on) appropriately during the training. An errorless attempt to retrieve the required part of the intervention from the Smartphone for more than three attempts will be considered to be successful training.

After successful training, the Smartphone enabled educational intervention package will be provided to

the participants for use at their home for the next 4 weeks. Participants will also be encouraged to contact the study leader (SK) if they have any concerns regarding Smartphone operation during these 4 weeks.

Assessment of outcomes

The primary outcomes of the pilot phase will be the feasibility and acceptability of the intervention. In addition to these outcomes, assessment of outcomes relating to the extent of disability and independence in activities of daily living will be carried out using the Modified Rankin scale³⁷ and Barthel Index,³⁸ respectively. Assessment of these outcomes will inform the feasibility of using these outcome assessment tools for future trials of the intervention. Details of the outcome assessment of phase 3 are explained in [table 2](#).

Analysis plan for the pilot phase

STATA will be used for analysis of the data in the pilot phase. Outcomes measuring the difference in proportions will be analysed using the χ^2 test or Fisher's exact test. Outcomes measuring the difference in

means will be analysed using the paired student t test or Wilcoxon matched pairs signed rank-sum test. Multivariate analysis using logistic regression techniques will also be conducted. To adjust for the imbalances in baseline characteristics, stratified analysis will be conducted or Mantel-Haenzel method will be used in the analysis.

Stakeholder workshop

The study findings will be shared during the final stakeholder workshop at the end of the pilot testing (phase 3).

Expected outcomes of this research study

This study seeks to develop and evaluate a Smartphone-enabled carer-supported educational intervention for management of post-stroke disability in India. Empirical exploration of this strategy will provide information on pragmatic solutions required to address the growing needs due to stroke disability in India and in other resource constrained settings. This research will provide an opportunity to develop

Table 2 Details of the outcome assessment for the pilot testing phase

Outcomes	Description
Feasibility	<p>A list of indicators will be developed during the pilot phase of the research study to assess feasibility of the intervention. This will include</p> <p><i>Feasibility of recruitment:</i></p> <p>Time taken to recruit the proposed number of participants</p> <p>Proportion of eligible participants identified</p> <p>Proportion of participants who consented in relation to participants who are eligible</p> <p>Reasons for exclusion</p> <p><i>Training:</i></p> <p>Number of participants successfully trained from the number of participants recruited for training</p> <p>Time taken for training by participants in different age-group, stroke severity and other factors (eg, experience of using a Smartphone)</p> <p>Training needs of participants in different age-groups, stroke severity and other factors</p> <p><i>Study processes:</i></p> <p>An in-built mechanism will be configured onto the Smartphone application to monitor the use of the intervention by participants. These indicators include:</p> <p>Proportion of participants ever using the application</p> <p>Proportion of participants using the application every week</p> <p>Proportion of participants using the application every day</p> <p>Proportion of participants using it for more than 1 h</p> <p>Proportion of participants requiring carer support</p> <p>Proportion of participants and carers successfully trained in using the application</p> <p>Proportion of participants accessing specific contents from the intervention</p> <p>Proportion of participants contacting the trainer/investigator for support</p> <p>Proportion of participants adhering to study protocol</p> <p>Reasons for non-adherence</p> <p><i>Follow-up:</i></p> <p>Number of drop-outs</p> <p>Reasons for dropping out</p>
Acceptability	<p>During the follow-up at the end of 4 weeks, a patient experience assessment will be conducted in order to understand the reasons for adherence or non-adherence, using a small questionnaire that will be developed for this purpose, soon after the end of phase 2 (once the intervention is ready)</p>
Functional outcomes	<p>Extent of disability—Modified Rankin Scale</p> <p>Activities of daily living—Barthel Index</p>

a patient-centred educational intervention for management of post-stroke disability that is relevant to the context of low- and middle-income countries. Findings from the research will also provide valuable information about the resources required to deliver such interventions in resource-constrained settings.

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Contributors SK conceived and designed the study, and drafted the manuscript. GVSM and HK played a crucial role in conception of the research study and provided substantial guidance in designing the research study. SK and SG provided scientific and methodological advice, related to conception and designing of the research study.

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Competing interests None declared.

Ethics approval London School of Hygiene and Tropical Medicine, Public Health Foundation of India and Hospital Ethics Committee (VHS Hospital).

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Data sharing statement This is only a protocol of a formative research study and we are in the process of data collection at present.

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Chapter 3

Systematic Review of the Literature

Preamble

This Chapter constitutes the review of literature carried out for this doctoral research study. It includes two systematic reviews and a detailed documentation of the challenges that one might experience while attempting to understand the epidemiology of stroke in India as sub chapters.

Chapter 3.1

A Systematic Literature Review of the Incidence and Prevalence of Stroke in India

Preamble

This chapter is a systematic review undertaken to investigate the epidemiology of stroke in India. It is essential to understand about the magnitude of stroke in India to design and develop an intervention that is relevant to the needs of those affected. Therefore, a detailed non-systematic review was initially undertaken on this topic in 2012 and it was published as an updated stroke factsheet in the resource page of the South-Asian Centre for Chronic Diseases, India (SANCD). This exercise provided a general understanding about stroke in India. However, the exact magnitude of the problem was not very clear from this general literature review. Therefore, I also conducted a systematic review on the epidemiology of stroke in India to gain an in-depth understanding of the magnitude of stroke in India.

This was the first ever attempt to review the incidence and prevalence of stroke in India systematically. This systematic review was submitted to the Indian Journal of Medical Research (IJMR) in April last year. Comments from the peer reviewers were addressed and the manuscript was re-submitted. The paper is currently accepted for publication and in press. The manuscript of this research paper is included as a chapter in this section.



RESEARCH PAPER COVER SHEET

PLEASE NOTE THAT A COVER SHEET MUST BE COMPLETED FOR EACH RESEARCH PAPER INCLUDED IN A THESIS.

SECTION A – Student Details

Student	SURESHKUMAR KAMALAKANNAN
Principal Supervisor	PROF GVS MURTHY
Thesis Title	Development and evaluation of a Smartphone-enabled Carer-supported Educational intervention for management of disabilities following stroke in India

If the Research Paper has previously been published please complete Section B, if not please move to Section C

SECTION B – Paper already published

Where was the work published?	Not Applicable		
When was the work published?	Not Applicable		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion	Not Applicable		
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Where is the work intended to be published?	Indian Journal of Medical Research
Please list the paper's authors in the intended authorship order:	1. K Sureshkumar, 2. G V S Aashrai, 3. G V S Murthy, 4. Shifalika Goenka 5. Hannah Kuper
Stage of publication	Submitted

SECTION D – Multi-authored work

<p>For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)</p>	<p>I conceived the study, designed the study, collected the data and analysed study data under the guidance of my supervisors Prof GVS Murthy and Dr Hannah Kuper. I developed the search strategy and ran the search in different databases. I took help from one of the co-author to do hand search and grey literature. I also took help from the co-author to collect, screen, review and analyse the study data. I also wrote the first draft of the manuscript and prepared subsequent revisions with consideration of comments from my supervisors and other co-authors.</p>
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Student Signature: _____

Date: 7/8/2015

Supervisor Signature: _____

Date: 7/8/2015

3.1. A Systematic Literature Review of the Incidence and Prevalence of Stroke in India

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3.1. A Systematic Literature Review of the Incidence and Prevalence of Stroke in India.

Abstract

There has been over a 100% increase in incidence of stroke in Low and Middle-Income Countries, including India, from 1970-79 to 2000-08. Lack of reliable reporting mechanisms, heterogeneity in methodology, study population, and small sample sizes in existing epidemiological studies make an accurate estimation of the stroke burden in India very challenging. We conducted a systematic review of all epidemiologic studies on stroke in India to document the exact magnitude of stroke.

All population-based, cross-sectional studies and cohort studies from India which reported the stroke incidence rate or cumulative stroke incidence, and/or the prevalence of stroke in participants from any age group, were included. We searched electronic databases (Ovid, Pub Med, Medline, Embase and Indmed) and studies from 1960-2014 were included. Two reviewers independently screened the titles and abstracts of the search results and identified studies to be included in the review.

We identified 629 independent titles for screening, of which eight population-based cross-sectional studies were eligible for inclusion. Given the heterogeneity in the studies, a meta-analysis was not carried out and the results are discussed as a narrative. The cumulative incidence of stroke ranged from 105-152/100,000 persons per year, and the crude prevalence of stroke ranged from 44.29/100,000 persons to 559/100,000 persons in different parts of the country over the past decade. These values are much higher than those reported from the High Income Countries.

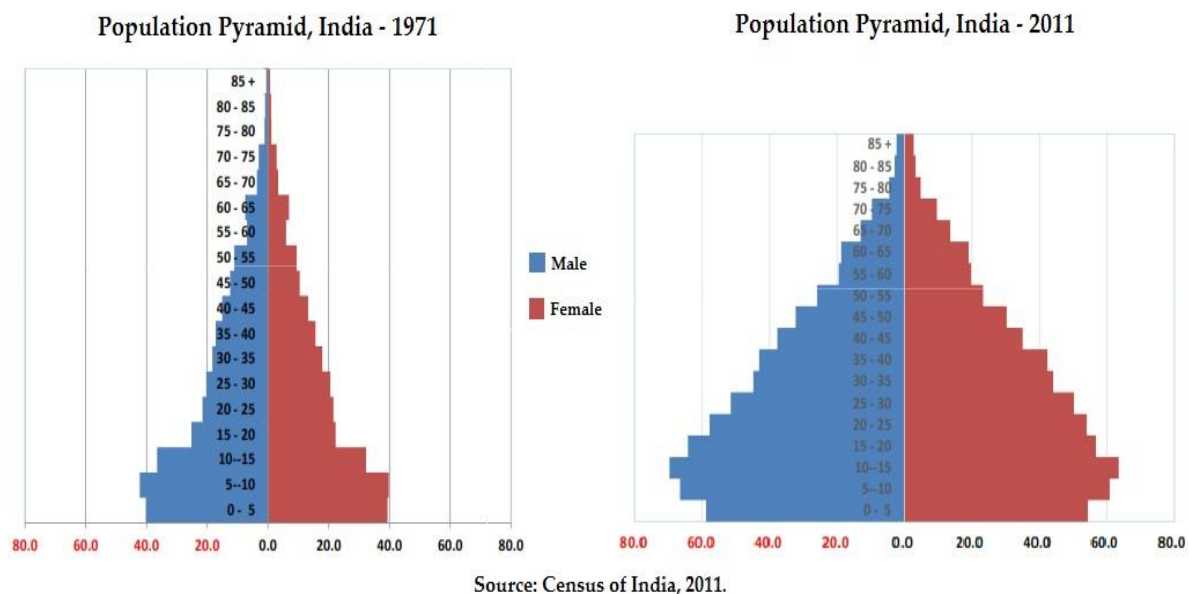
A paucity of good quality epidemiological studies on stroke in India emphasises the need for a coordinated effort at both the state and national level to study the burden of stroke in the Indian community. Future investment in population-based epidemiological studies on stroke in India would lead to better preventive measures against stroke and better rehabilitation measures for stroke-related disabilities.

Keywords: Epidemiology, Incidence, Prevalence, Stroke, Systematic Review.

3.1.1. Background

As a part of the literature review process, a systematic review on incidence and prevalence of stroke in India was carried out. India is one of the largest - and the second most-populous - countries in the world, with more than 1.21 billion people ¹. It is one of the world's fastest-growing economies with an annual GDP growth rate of 5.8% over the past two decades ². As one of the largest countries of the LMICs, it has been experiencing significant demographic, economic and epidemiological transition during the past two decades (Figure 3.1.1) ¹. These have resulted in an increase in life expectancy and, consequently, an increase in the ageing population ².

Figure-3.1.1: Demographic transition in India (1971 – 2011)



Reliable morbidity and mortality estimates for stroke in India are very limited ³⁻⁵. Mortality statistics for India do not have information on the cause of death ⁶. Unless someone dies in a hospital, it is difficult to ascertain the cause of death. Therefore, it is not possible to identify the exact cause of death from the mortality registers available in India ⁶⁻⁸.

In addition, available research information on the epidemiology of stroke in India suffers from various methodological flaws, including small and variable sample sizes, inconsistent diagnostic criteria, different case definitions and survey strategies. Most of these studies are cross-sectional in nature and the primary objectives in each of these studies are also diverse⁹⁻¹⁰. Given the paucity of data and lack of reliable reporting mechanisms, understanding the epidemiology of stroke in India is highly challenging. Hence we intended to conduct a systematic review of epidemiological studies of stroke in India.

3.1.2. Objective

The objective of this review was to investigate the incidence and prevalence of stroke in India. This facilitated investigation of consistency of evidence across studies and allowed us to explore the differences across them¹¹. Thus, this review gave us a more robust picture about the extent and impact of stroke in India.

3.1.3. Methods

This systematic review was prepared and completed in compliance with the structured format outlined in the Cochrane Handbook for systematic reviews¹¹.

Criteria for Selecting Studies for this Review

a. Types of studies

All population-based, cross-sectional studies and cohort studies investigating the prevalence and incidence of stroke in India were included in the review. Information from hospital-based studies was not included in estimating the prevalence/ incidence, but such information was used only to compare findings.

b. Types of participants included

Participants of any age group, diagnosed with stroke as defined by the WHO ¹, were included.

c. Types of outcome measures

Studies had to report stroke incidence rate or cumulative incidence and/or prevalence to be included in the review.

Search Methods for Identification of Studies

a. Electronic searches

Five electronic databases (Ovid, Pub-med, Medline, Embase and Indmed) were searched using appropriate Medical Subject Heading (Mesh) terms to identify relevant publications. The initial search was conducted in 2012 and subsequently updated in 2014. Studies published in English between January 1990 and December 2014 and studies that used the WHO case definition for stroke ¹ were considered. Studies published before 1990 were excluded because of different case definitions, survey methods and data presentation. The reference lists from retrieved studies were also checked to identify additional studies. The search strategy for Pub-med is detailed in appendix 1.

b. Searching other resources

Grey literature was searched via proceedings from stroke conferences, Google, Indian newspapers and print media.

Data Collection and Analysis

a. Selection of studies

We designed a broad search strategy for Pub-med and used the same strategy for other databases. Two reviewers independently screened the titles, abstracts and full texts of the

identified studies and a third reviewer was available to address any disagreement between the two reviewers. Two reviewers independently assessed the methodological quality of the included studies. In order to assess the methodological quality of the included studies, the STROBE statement (Strengthening the Reporting of Observational Studies in Epidemiology) was used as guidance ¹²⁻¹³. A third reviewer was available to address any disagreement between the two reviewers.

3.1.4. Results

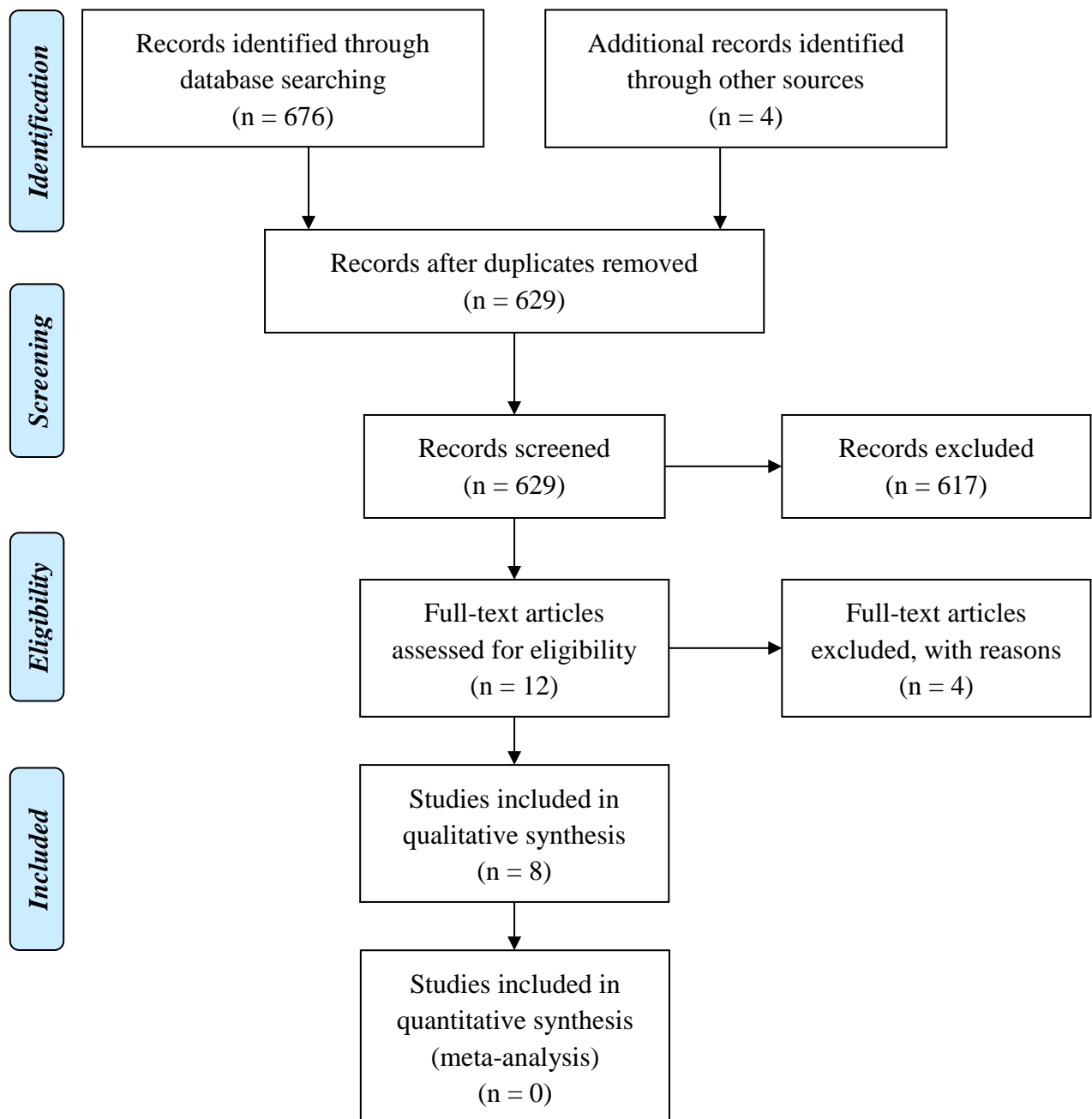
The search strategy retrieved a total of 676 relevant records. After removing the duplicates, we identified 629 records for screening. After independent screening of the records, we were able to identify 12 records that were eligible for full-text review. After reviewing the full text of these 12 records, we identified eight population-based cross-sectional studies that met our inclusion criteria. The remaining four studies excluded from the review were hospital-based studies. Information from hospital-based studies was included only for the purpose of discussion. We did not identify any cohort studies in our search and study selection process. Figure 3.1.2 details the flow chart of the study selection process.

a. Results of the search

We included eight studies that met the inclusion criteria for the review. Of the eight population-based studies, two estimated the prevalence of neurological disorders, including stroke ¹⁴⁻¹⁵, two estimated both the incidence and prevalence of stroke ¹⁶⁻¹⁷, two looked exclusively at cumulative stroke incidence ¹⁸⁻¹⁹, while two studies looked exclusively at stroke prevalence ²⁰⁻²¹. There were substantial variations in the sample size, survey methods and case definitions among the included studies. Given the heterogeneity among the included studies, we did not carry-out a meta-analysis and, instead, summarised the findings

as a narrative. The results of the included studies are provided in Table 3.1.1.

Figure 3.1.2: Flow chart of the systematic study selection process. Adapted from the PRISMA statement¹³



b. Study locations

During our search process, we could not find any national level stroke survey that included all/most of the Indian states. Studies included in the review were specific to certain states within India (Figure 3.1.3). Of the eight studies included in the review, two were from Kolkata ¹⁶⁻¹⁷, the capital city of West Bengal; three were from Mumbai ^{18, 20-21}, the capital city of Maharashtra; one study from Rohtak in Haryana ¹⁹; one from Srinagar in Jammu & Kashmir ¹⁵; and one from Bangalore in Karnataka ¹⁴.

Figure 3.1.3: Location of studies included in the review



c. Study settings

One study looked at stroke prevalence in both urban and rural areas ¹⁴. All other studies were conducted only in urban areas ¹⁵⁻²¹.

d. Outcomes

i. Incidence of stroke in India

Four of the studies included in the review estimated cumulative stroke incidence - two in urban Kolkata¹⁶⁻¹⁷ and two in Mumbai²⁰⁻²¹. In the two Kolkata studies, ascertainment of new stroke cases was through a two-stage survey. The first stage was a door-to-door survey in a defined target population conducted by trained field investigators to ask about the occurrence of stroke in the household in the past year, and the second stage was a clinical examination performed by a neurologist. Computerised tomography (CT) reports, if available, were used by the neurologist to confirm diagnosis in both these studies.

The first study was conducted in Kolkata during 1998-1999¹⁶. The age-adjusted cumulative incidence of stroke in the study conducted was estimated to be 105/100,000 people per year. Stroke incidence was higher among women and people aged 40 years and older. Only those who survived a stroke were enumerated in the survey and the study population was surveyed only once during the specified time period (households surveyed in the early part of the year were not rechecked in the latter part of the year).

The other study was conducted in Kolkata during the years 2003-2005¹⁷. The age-adjusted cumulative incidence of stroke was estimated to be 145/100,000 people per year. There was a progressive increase in stroke incidence as the age increased. Cumulative incidence of stroke was higher among women (178/100,000) compared to men (117/100,000). The 30-day case fatality rate in the study was 41%. However, confirmatory CT diagnosis was available only for 51% of the identified new cases, and only one-tenth of the new cases had death certificates to identify the exact cause of death.

Two studies estimated cumulative incidence of stroke in a well-defined geographic area in Mumbai at two different time periods. As a part of the Mumbai stroke registry surveillance, using the WHO STEPwise approach to stroke surveillance (STEPS) guidelines, Dalal et al conducted a two year survey (January 2005 to December 2006) in a defined geographical area. The survey included all three of the WHO STEPS for surveillance ²⁰. The age-standardised cumulative incidence of First Ever Strokes (FES) in this study was 152/100,000 persons per year. The age-standardised cumulative stroke incidence among men and women in this study was 162 and 141 per 100,000 persons per year, respectively. Two-thirds (67.2%) of the FES cases in this study were identified at hospital facilities (WHO Step -1). The resurvey was conducted in the same district in 2009 by the same team and by using an identical protocol as before ²¹. The age-standardised cumulative incidence of FES in the resurvey was 137/100,000 persons per year.

Overall, the estimates from the included studies show that the cumulative annual incidence of stroke in urban Kolkata ranges from 105-145/100,000 persons between 1998 and 2005. The age-standardised cumulative annual incidence of stroke in Mumbai was 152/100,000 persons in 2005 and 137/100,000 persons in 2009. Given the heterogeneity among these studies, we cannot combine the results. More details about the cumulative incidence and stroke prevalence reported in the included studies are provided in Table 3.1.1.

ii. Prevalence of stroke in India

We identified six population-based cross-sectional studies that estimated the prevalence of stroke¹⁴⁻¹⁹ (Table 3.1.1). A population-based survey of neurological disorders in Bangalore during 1993-1995 had systematically identified prevalent stroke cases from a defined urban and rural area¹⁴. The age-adjusted prevalence of stroke in this study was 262/100,000 persons. Prevalence of stroke in rural areas was higher (165/100,000) compared to the urban areas (136/100,000). The Bangalore study¹⁴ and two Kolkata-based studies¹⁶⁻¹⁷ showed a rising trend in the prevalence of stroke, with 262/100,000 persons affected during 1993-1995, 334/100,000 in 1999 and 545/100,000 in 2005.

A two-year survey (2006-2008) was conducted at Dharavi in Mumbai to study the prevalence of stroke and post-stroke cognitive impairment in the elderly¹⁸. It was a multi-stage survey using the WHO screening tool for stroke, with minor modifications. The age-standardised stroke prevalence in the study was 4870/100,000 persons. The stroke prevalence in men was 6740/100,000 persons. It was almost twice the level observed in women (3480/100,000) in this study. Given the participant inclusion criteria, findings from the study indicate the prevalence of stroke only among people aged ≥ 60 years.

The prevalence of neurological disorders was studied in Ganderbal block, a rural area in Srinagar, the capital of Jammu and Kashmir¹⁵. The survey was conducted in two stages for a period of five months between October 1999 and March 2000. This study showed that the crude prevalence of stroke in Ganderbal block was 559/100,000 persons. Of the stroke survivors identified in the survey, 74% had Haemorrhagic stroke.

Prevalence of stroke was also studied in Rohtak City in Haryana in 1974²² and the same catchment area was resurveyed 15 years later in 1999¹⁹. Information about the training provided to conduct the survey was not reported. The crude prevalence of stroke was 44.28/100,000 persons in the 1999 study. Prevalence of stroke amongst men (46.78/100,000) was found to be higher than among women (41.52/100,000). Prevalence of stroke in the urban and rural populations was similar. The overall stroke prevalence was 7.20% lower than the survey completed 15 years earlier in the same area. The trend in stroke prevalence reported in the included studies is shown in Figure 3.1.4.

c. Information from hospital-based studies on stroke

Given the insufficient number of population-based studies, information from hospital-based studies was also reviewed. Hospital-based stroke registries in India have estimated cumulative stroke incidence based on the WHO STEPs²³ guidelines for stroke surveillance (Table 3.1.2)²⁴⁻²⁷.

Hospital-based stroke registries at Chennai and Bangalore have not described the catchment population and, hence, it was not possible to calculate cumulative incidence of stroke at population level from these studies²⁴⁻²⁵. The Trivandrum stroke registry study estimated stroke incidence from an urban and rural convenience sample²⁶. However, most of the rural patients in the study did not report at the selected hospital sites. The Ludhiana stroke registry estimated an age-adjusted cumulative stroke incidence of 155/100,000 people during the year 2011²⁷.

Table 3.1.1: Incidence and prevalence of stroke in India – details from included studies ¹⁴⁻²¹

First author	Year	Location	Sample size	Mean age of population (range)	Number of cases of stroke identified	Cumulative incidence /100,000 people	Age-adjusted cumulative incidence /100,000 people	Crude prevalence /100,000 people	Age-adjusted prevalence /100,000 people	WHO Step
Gourie-Devi	1993 - 1995	Bangalore, Karnataka	102,557	Age range (<15 to 61+)	154	-	-	150 Rural :165 Urban :136	262	3
Banerjee TK	1998-1999	Kolkata, West Bengal	50,291	Age range (20 to 90+)	74	36	105	147	334	3
Salaam MD	1999-2000	Srinagar, Jammu & Kashmir	10368	>55 years	58		-	559	-	3
Dhamija RK	2000	Rohtak, Haryana	79046 –Urban 51,165 - Rural	Male:61.6 Female:59.0	35 – Urban 23 - Rural	-	-	Urban - 44.28 (CI. ± 1.43) Rural - 44.95 (CI. ± 1.8)	109	3
Das	2003-2005	Kolkata, West Bengal	52,377	≥ 60 years (11%-17%)	247	123.15 (102.46-232.50)	145.30 (120.39-174.74)	471.58 (414.99-533.83)	545.10	3
Dalal PM	2005-2006	Mumbai, Maharashtra	156,861	Age range (25 to 94+)	521	145 (120-170)	152 (132-172)	-	-	1,2&3

Mukhopadyay	2006-2008	Mumbai, Maharashtra	1726	66.0 years (60-105 years)	66	-	-	3.82/100 (3.01 – 4.84)	4.87/100 (3.76 – 6.23)	3
Dalal PM	2009	Mumbai, Maharashtra	174,398	Age range (25 to 94+)	223	127.8 (110-150)	137 (119-155)	-	-	1,2&3

Figure 3.1.4: Trends in prevalence of stroke in India

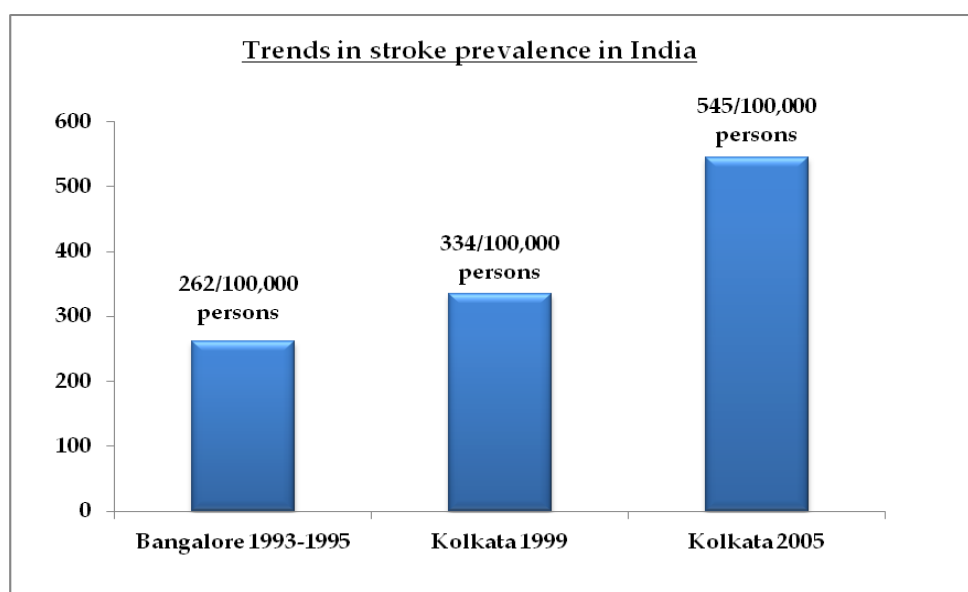


Table 3.1.2: Age-adjusted cumulative stroke incidence and the number of new stroke cases from stroke registries²⁴⁻²⁷

Place	Number/ Types of hospitals within the registry	Period of the study	Duration of surveillance	WHO STEPs stage	Catchment population	Number of new cases or age-adjusted cumulative incidence /100,000 people
Chennai	Two private hospitals	2003 – 2004	Twelve months	Step 1	not known	402 cases
Bangalore	One government, two private hospitals	2005	Six months	Step 1 & 2	not known	1,174 cases
Trivandrum	Group of hospitals in rural & urban in catchment area	2005	Six months	Step 1 & 2	Rural: 185000 Urban: 741000	138 Rural 135 Urban
Ludhiana	Major hospitals, scan centres, general practitioners	2011	Twelve months	Step 1 & 2 (modified)	Urban 1398467	155 cases

d. Methodological quality assessment

Two reviewers independently assessed the methodological quality of the included studies. The STROBE statement (Strengthening the Reporting of Observational Studies in Epidemiology) was used as guidance for this assessment ¹². Table 3.1.3 summarises the methodological quality of all the studies included in the review. We did not identify any cohort studies investigating the epidemiology of stroke in India. Methodological details of the studies were not fully reported in the published version of the included studies. Three studies did not report how participants for the survey were selected ^{15, 20-21}. Four studies reported the use of quality control procedures for case detection, in terms of confirmatory diagnosis by a neurologist and also by the CT scan ¹⁴⁻¹⁸.

Two studies that followed the complete WHO STEPs surveillance method did not report the ways in which mortality statistics were calculated, especially when the cause of death was not mentioned in the death registers ²⁰⁻²¹. These studies did not report the ways in which hospital-based information, mortality statistics and the survey information were combined to arrive at the estimates. Methods of case ascertainment also varied among the studies included in the review. In terms of case definitions, some studies included only First Ever Strokes, while some included all kinds of strokes. Some studies included only the stroke survivors, while a few studies also included those who died of a stroke.

Table 3.1.3: Methodological quality of the studies included in the review¹⁴⁻²¹.

Author/ Year	Specific objective	Study design	Method of participants selection described	Data sources	Efforts to address source of bias	Explanation on sample size estimation	Limitations discussed	Generalisability of the findings
Gourie- Devi 2004	To determine the prevalence and pattern of neurological disorders in urban and rural areas	Cross - sectional	Yes	Survey	Large sample size; Systematic sample selection and piloting verification of study procedures	Yes	No	May be generalisable to urban & rural areas of cities with similar demographic characteristics
Banerjee 2001	To determine the prevalence and incidence of stroke in urban Kolkata	Cross - sectional	Yes	Survey	The sensitivity of the screening method (72%) was not satisfactory	No	Yes	May be generalisable to urban areas in cities with similar demographic characteristics
Dalal 2012	To calculate the incidence of First Ever Strokes during a resurvey	Cross - sectional	No	Survey	No	No	No	May be generalisable to only First Ever Strokes from an urban area in cities with similar demographic characteristics
Dalal 2008	To describe observations made during a survey using WHO STEPS tool	Cross - sectional	No	Survey	No	No	2/3 rd of the cases identified were from hospitals and not the community.	May be generalisable to only First Ever Strokes from an urban area in cities with similar demographic characteristics

Das 2007	To determine the incidence and prevalence and case fatality rates of stroke	Cross – sectional	Yes	Survey	Large sample size; Study quality control measures taken	Yes	Yes	May be generalisable to urban areas in cities with similar demographic characteristics
Mukhop adyay 2012	To determine the prevalence of stroke in urban slum-dwellers aged 60 years and above	Cross – sectional	Yes	Survey	Large sample size; Study quality control measures taken	Yes	Yes	May be generalisable to urban slum dwellers aged 60 and above in cities with similar demographic characteristics
Salaam 2002	To determine the prevalence of all neurological disorders	Cross – sectional	No	Survey	No	Yes	No	May be generalisable for people aged over 14 in rural areas with similar demographic characteristics
Dhamija 2000	Prevalence of stroke	Cross – sectional	Yes	Survey	No training for data collection	No	Yes	May be generalisable for people aged over 20 in cities with similar demographic characteristics

3.1.5. Discussion

Stroke is one of the leading causes of death and disability in India. Studies included in this review show that the crude stroke prevalence during the past two decades in India ranges from 44.29/100,000 persons to 559/100,000 persons in different parts of the country ⁷. The cumulative incidence of stroke in India varies widely, from 105-152/100,000 person per year, during the past two decades in different parts of the country ⁷. These estimates on stroke incidence and prevalence are found to be higher than those reported from High Income Countries ²⁸. In a global systematic review on stroke epidemiology, the age-adjusted stroke incidence rates in HICs were reported to be 94 /100,000 person-years during 2000-2008 ²⁸. Other estimates show that stroke incidence fell by 42% during the past four decades in HICs (from 163/100000 person-years during 1970-79) while they increased by 100% in LMICs ²⁸ (i.e. from 52/100,000 person-years in 1970-79 to 117/100,000 person-years in 2000-08). Information from the studies included in this review showed that the cumulative stroke incidence reported in two major metropolitan cities of India (Mumbai and Kolkata) to be much higher than that reported in High Income Countries (HICs) ²⁸. Thus, the findings from the global stroke review support the findings from this review.

Although this review describes the silent epidemic of stroke that India is experiencing, it might not reflect the complete picture of the situation. There are two reasons for this. Firstly, the estimates reported from the studies included in the review are likely to be underestimates. Only two studies included in the review followed all three steps of the WHO STEPS guidelines for stroke surveillance ²³. Hence, the remaining studies could have only identified individuals who survived a stroke and not those who died due to stroke. Given the lack of reliable information from death registers on the cause of death in India ²⁹, estimates on stroke

mortality in the two studies that followed the WHO STEPs guidelines may not necessarily be true estimates. Potentially, it might be a gross underestimate.

In addition, stroke survivors in India can end up in any hospital that they prefer or that is easily accessible for stroke care. Referral pathways and systematic care for stroke survivors are poorly organised by government health services across the country ⁷. Therefore, calculating stroke incidence and prevalence using data available from hospital-based stroke registers might not provide reliable estimates. Unless all the hospitals (including traditional healers and alternative medical practices) in a particular geography are included during the survey, it might not be possible to use this kind of data to arrive at accurate estimates.

Secondly, most studies included in the review were conducted in urban metropolitan cities. Possible reasons for this could be the logistical convenience and availability of resources and trained personnel in these cities ⁵. Of the eight studies included in the review, only two studies looked at the urban- rural distribution of stroke prevalence. Given the demographic characteristics of India, where about 80% of the population live in rural settings, it is important to investigate the epidemiology of stroke in the rural regions of India rather than the cities alone. This could provide more reliable estimates on the magnitude of the problem in India.

In light of the relatively few studies and the variation in their study methods, it is not possible to generalise the findings from the included studies to the entire country. All the studies that we reviewed were cross-sectional. Although four studies did calculate the cumulative incidence based on cross-sectional data, the validity of the results would not be as robust as that of a cohort study. Studies included in the review were also heterogeneous in terms of

their participant selection, case definition and survey methodology. Hence, a comprehensive meta-analysis was not possible ¹¹. It would be useful if future studies used consistent case definitions and survey methods to allow for this.

Stroke epidemiology in India has been investigated in different parts of the country in different ways. This is the first review on stroke epidemiology in India that has been systematically conducted. Unlike other reviews conducted previously in India, this systematic review was specific to stroke and included only population-based studies. In a country like India, there are no well-established systems for collecting and managing information on various diseases, especially stroke. Clearly defined and systematically conducted reviews can provide useful information for decision-makers to plan programmes and policies for stroke. In addition to stroke estimates, this review also reported the methodological quality of the evidence available. This might facilitate stroke researchers to appropriately design future studies on stroke that are methodologically robust and that would provide precise and reliable stroke estimates.

In the light of the scarce and variable data regarding stroke epidemiology in India, it is imperative that more efforts be directed at data acquisition and analysis. Stroke registries can act as important reservoirs of such information. Although there has been some effort in certain hospitals to understand stroke epidemiology through hospital-based registries, it is important to initiate a government-regulated, state and national population-based stroke registry in India. This should include all possible stroke detection facilities and ensure real time documentation of stroke in these facilities, as opposed to having a stroke registry where interested health facilities can add stroke data on a voluntary basis ⁽³⁰⁻³¹⁾. It could be extremely useful to make it mandatory for all stroke care facilities to share their data with the

current registry and systematically manage the substantial information that could be collected in this way. Such valuable information would benefit the country in the following ways:

(i) Epidemiological information obtained from population-based registries could be used to enable evidence-informed advocacy and policy changes for allocation of funds for stroke-related programmes ³¹.

(ii) Since the management of stroke varies according to aetiology, the data on risk factors and most prevalent stroke subtypes would guide us in preparing stroke treatment protocols according to the prevalence of various aetiologies / risk factors in a community ³².

(iii) The data on case fatality would facilitate evaluation of standards and efficacy of acute post-stroke treatment ⁷.

3.1.6. Conclusion

There is a paucity of epidemiological studies on stroke in India, which emphasises the need for a focused, coordinated effort at the state and national level to study the extent of stroke in the community, plan programmes for primary prevention of stroke and to address the existing magnitude of stroke-related disability in the country. Given the disabling nature of the condition and available evidence on the silent stroke epidemic in India, the rehabilitation needs of stroke survivors in India are expected to be substantial. Thus, future investment in the study of epidemiology of stroke in India would lead to development of better preventive measures against stroke and related mortality. It can also enhance organising cost-effective stroke care services and better rehabilitation measures to address the unmet needs of stroke survivors.

Chapter 4.2

**Challenges in Understanding the Epidemiology of
Acquired Brain Injuries in India**

Preamble

This chapter describes the common challenges that a researcher with an interest in understanding the epidemiology of stroke and other acquired brain injuries in India might come across and the potential solutions to enhance their understanding while making such an attempt. It was quite challenging to collate relevant studies and understand the exact epidemiology of stroke in India through the systematic review described earlier. Studies included in the review were highly heterogeneous and therefore the review was described narratively.

During this systematic review completion process, efforts were taken to systematically document the challenges in gaining a comprehensive understanding about the epidemiology of stroke in India. This is especially to inform future research on this topic. A research paper was written based on this documentation and it was published in the Annals of Indian Academy of Neurology. The published version of this research paper is included as a chapter.

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Principal Supervisor	PROF GVS MURTHY
Thesis Title	Development and evaluation of a Smartphone-enabled Carer-supported Educational intervention for management of disabilities following stroke in India

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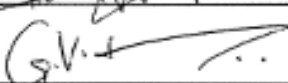
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Short Communication

Challenges in understanding the epidemiology of acquired brain injury in India

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Abstract

An acquired brain injury (ABI) is an injury to the brain, which is not hereditary, congenital, degenerative, or induced by birth trauma. In India, rapid urbanization, economic growth and changes in lifestyle have led to a tremendous increase in the incidence of ABI, so much so that it is being referred to as a 'silent epidemic'. Unlike developed countries, there is no well-established system for collecting and managing information on various diseases in India. Thus it is a daunting task to obtain reliable information about acquired brain injury. In the course of conducting a systematic review on the epidemiology of ABI in India, we recognized several challenges which hampered our effort. Inadequate case definition, lack of centralized reporting mechanisms, lack of population based studies, absence of standardized survey protocols and inadequate mortality statistics are some of the major obstacles. Following a standard case definition, linking multiple hospital-based registries, initiating a state or nationwide population-based registry, conducting population-based studies that are methodologically robust and introducing centralized, standard reporting mechanisms for ABI, are some of the strategies that could help facilitate a thorough investigation into the epidemiology and understanding of ABI. This may help improve policies on prevention and management of acquired brain injury in India.

Key Words

Acquired brain injury, challenges, epidemiology, India



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What is Acquired Brain Injury?

An acquired brain injury (ABI) is an injury to the brain, which is not hereditary, congenital, degenerative, or induced by birth trauma. It is an injury to the brain that has occurred after birth.^[1] The causes of ABI can be broadly categorized into two main types: 'Traumatic' and 'Non-traumatic' causes. "Traumatic brain injury is damage to the brain resulting from an external mechanical force, such as rapid acceleration, impact, blast waves, or penetration by a projectile".^[2] Non-traumatic brain injury is caused by an illness or disease of the brain (not due to trauma). It results from internal forces such as infections and malignancies.^[3]

Some of the non-traumatic causes of ABI include cerebro-vascular accident (stroke) which is "A focal (or at times global) neurological impairment of sudden onset, and lasting more than 24 hours (or leading to death), and of presumed vascular origin"^[4], tumor, vascular malformations and cerebral infections.^[5]

Understanding the Epidemiology of ABI

ABI is an important public health problem with a significant global impact. However, the problem experienced by those affected, such as impairments in cognition and perception, are often not visible. Hence it has been referred to as a 'silent epidemic'.^[6] Among the various causes of ABI, traumatic brain injury and stroke are the leading causes of death and disability worldwide.^[7] Traumatic brain injury (TBI) and stroke are the two main causes of ABI that have reached epidemic proportions and are regarded as important public health problems in India. Rapid urbanization, economic growth and life style changes are the reasons for the growing burden of ABI in India.^[8] In India, over 100,000 people die due to road traffic accidents each year^[9] and nearly 50-60% of them are hospitalized for

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brain injury.^[10] The increasing prevalence of hypertension in the country has resulted in an increase in the number of stroke cases by 17.5% during the past 15 years.^[11] Thus, understanding the epidemiology of ABI in India could help plan appropriate interventions and address the burden accordingly.

Our systematic review identified eight studies on stroke^[12-19], two studies on traumatic brain injury,^[20,21] two studies on brain tumor^[22,23] and one study on neurological disorders that included brain infections and stroke.^[10] Of the 13 studies, eight studies on stroke were population based, cross-sectional studies. All the remaining studies were hospital based longitudinal registries or cross-sectional studies. None of the identified studies looked at the incidence and prevalence of ABI resulting from all the causes together. Two studies estimated

the incidence and prevalence of stroke exclusively.^[24,25] One study looked at the prevalence of brain infections and stroke together with other neurological disorders.^[10]

Table 1 depicts the heterogeneity among the studies identified and included for the review.^[12-24] We did not find any population based study on acquired brain injuries except for stroke. Each study has looked at a specific cause of ABI at various states and cities within India, using different study methods. Given these methodological challenges, it is difficult to combine the estimates from individual epidemiological studies to understand the exact magnitude of ABI in India.

In our systematic review, we identified several hospital based studies [Table 2]^[14-16,19]. Every hospital based study had assumed

Table 1: Incidence and prevalence of ABI in India—Details from included studies

First author	Year	Location	Sample size	Cumulative Incidence/100,000 people	Age adjusted cumulative Incidence/100,000 people	Crude prevalence /100,000 people	Age adjusted prevalence /100,000 people	WHO step
Stroke								
Dalal PM	2009	Mumbai	174,398	127.8 [110-150]	137 [119-155]	-	-	1,2&3
Mukhopadhyay	2006-2008	Mumbai	1726	-	-	3.82/100 (3.01-4.84)	4.87/100 (3.76-6.23)	3
Dalal PM	2005-2006	Mumbai	156,861	145 [120-170]	152 [132-172]	-	-	1,2&3
Das	2003-2005	Kolkata	52,377	123.15 (102.46-232.50)	145.30 (120.39-174.74)	471.58 (414.99-533.83)	545.10	3
Salaam	1999	Kashmir	10368	-	-	559	-	3
Banerjee TK	1998-1999	Kolkata	50,291	36	105	147	334	3
Gourie Devi	1993-1995	Bangalore	102,557	-	-	150 Rural: 165 Urban: 136	262	3
Dhamija RK	1991	Rohtak	79356	-	-	44.54 (CI:±1.12)	-	3
Traumatic Brain Injury								
Hsiao M	2001-2003	National retrospective survey	122000	62% head injury cases were reported during verbal autopsy				-
Yattoo	2004	Kashmir	Not Known	55 (Hospital incidence)	Identified 3861 TBI cases			-
Gururaj	2000-2001	Bangalore	Not Defined	Identified 7164 TBI cases			-	-
Tumors of Brain								
Yeole	1982-2003	Cancer registries in 5 Cities	Not Known	-	2.53 - 4.14 in Men 1.46 - 2.66 in Women	-	-	-
Ayub	2002-2006	Hospital based surveillance in Kashmir	Not Known	2.2 in Men 0.9 in Women	-	-	-	-
Post meningitic/encephalitic brain infection								
Gourie Devi	1993-1995	Bangalore	102,557	-	-	-	30	-

TBI = traumatic brain injury

Table 2: Age-adjusted cumulative stroke incidence and the number of new stroke cases from stroke registries

Place	Number/Types of hospitals within the registry	Period of the study	Duration of surveillance	WHO step stage	Catchment population	Number of new cases or age adjusted cumulative incidence/100,000 people
Chennai	2 private hospitals	2003-2004	12 months	Step 1	not known	402 cases
Bangalore	1 government, -2 private hospitals	2005	6 months	Step 1 & 2	not known	174 cases
Trivandrum	Group of hospitals in rural & urban in catchment area	2005	6 months	Step 1 & 2	Rural: 185000 Urban: 741000	138 Rural 135 Urban
Ludhiana	Major hospitals, scan centers, general practitioners	2011	12 months	Step 1 & 2 (modified)	Urban 1,398,467	155

that the maximum number of ABI cases would report only to the hospitals involved in the study. However, it is difficult to define the catchment population in any of the hospital based studies. People affected by ABI might end up in any hospital outside the geographic location of the study or they might reach the hospitals from an entirely different state or district outside the study location as there is no structured referral pathway in India. Thus, it implies a gross under-estimation of the incident cases and it is highly unlikely that findings from these studies reflect true estimates.

Challenges in Understanding the Epidemiology of ABI in India

Unlike developed countries, there is no well-established system for collecting and managing information on various diseases in India. Many factors hamper the efforts to precisely quantify the burden of acquired brain injury in India. Let alone the lack of reliable reporting systems, it is difficult to discover reliable statistics even from routinely collected data.^[11] Hence we would like to highlight some of the barriers to understanding the epidemiology of ABI in India.

1. By definition, ABI includes brain injuries of both traumatic and non-traumatic etiology. A wide range of causes contribute to the burden of acquired brain injury. Until now, the burden imposed by various causes had only been studied individually rather than in totality in India. Each study has looked at a specific cause of ABI at various places within India, using different study methods. Case ascertainment strategies and sample size in these studies also differed widely. Only one population based study conducted in Bangalore, looked at stroke and brain infections together with other neurological disorders.^[12] However, even this study did not adopt the definition of ABI strictly. The study considered neurodegenerative diseases and did not include traumatic brain injury. Given these methodological challenges, it is difficult to estimate the magnitude of ABI in the community from individual epidemiological studies.
2. Mortality statistics of India do not have information on the cause of death.^[13] Unless someone dies in a hospital that could provide information about the cause of death to these death registries in India, it is not possible to identify the exact cause of death from the mortality registers available in India. For example, TBI contribute to a significant proportion of deaths due to road traffic accidents (RTAs).^[14-17] In India, RTA investigation is carried out by the police/crime department and the information about the RTA is maintained by the National Crime Records Bureau (NCRB). But it does not collect information on cause of death. Given the context, under-reporting of RTA deaths by the police department have been reported in many studies.^[18,19] The recently published million death study on road injuries and death have highlighted the under-reporting of crude death rates by the NCRB which ranged from < 1% to about 80%.^[20]
3. Majority of the information on epidemiology of ABI is from hospital based studies. It is difficult to define the catchment population in any of the hospital based studies. Details from the hospital based stroke registries have been depicted in Table 2.

4. There is a lack of population based studies on the incidence and prevalence of ABI in India. There are no cohort studies on any of the causes of ABI.^[21] Cohort studies are vital to establish the incidence and impact of ABI in the community. Unfortunately, there has been no effort at the state, or the national level, to initiate such a study. Because of this, epidemiological parameters are often estimated from cross-sectional studies and these estimates may not be reflecting the true magnitude of the problem.
5. Lack of standardized survey protocols for assessing the incidence and prevalence of ABI in totality or from individual causes is also a challenge. Although the WHO STEP wise approach to surveillance for stroke is widely used in many countries including India^[22], the feasibility of using such a tool in the Indian context and the necessary revisions, to enhance feasibility of such protocols in the Indian context have not been optimally explored. Information from Table 2 highlights the variation in sample size, WHO surveillance STEPs, and whether catchment population was defined in each study. For example, studies have followed different WHO STEPs to their stroke surveillance which makes it difficult to arrive at the precise estimate of the incidence or prevalence from these studies. The estimates may vary among these studies because each study had followed only selective steps of the WHO STEPs surveillance procedures. Each of the population based studies [Table 1] had very different sample sizes. In some studies the catchment population was not defined. Hence, arriving at an estimate for incidence or prevalence was not possible in these studies. A limitation of the million death study is the use of lay person narratives to conduct the survey which may have led to inaccurate reporting.^[24] Similarly in some of the stroke studies, only first ever strokes were considered as a case. In some studies people with stroke who have died during the study have not been included as a case. This makes estimation of incidence and prevalence of ABI very difficult.
6. Ascertainment of cases for ABI studies in India doesn't ensure confirmatory radio-diagnosis. Case ascertainment strategies in most of the cross-sectional studies aimed at assessing the prevalence of ABI in India are based on questionnaire surveys and neurological examination.^[12] Confirmatory diagnosis through computerized tomography (CT) and magnetic resonance imaging (MRI) were not used as the basis for case ascertainment in many studies. Hence objectivity of the case ascertainment strategies used in epidemiological surveys of ABI in India is questionable.
7. Information from population-based registries is limited to very few hospitals in India. Some of the hospital-based registries in India propose themselves to be population based registers for certain causes of ABI. For example, the stroke registry and the cancer registry.^[23] However, these are sustained by voluntary contributions from a few hospitals from a defined catchment area. There are no regulations by concerned authorities to ensure compulsory documentation and reporting of epidemiological data on ABI to these registries.
8. There is a lack of data sharing and linkage between the existing registries to consolidate the available information and to regularly update it at a state, regional or country

level. This reduces the actual utility of such registries since a single hospital cannot catch a significant proportion of the population within a target area. Unlike developed countries, we do not have linkages between various government departments gathering information about ABI in India. For example, Information about RTAs from NCRB is not linked to the hospitals collecting longitudinal data on TBI in India in hospitals such as NIMHANS.^[10] Registries themselves are independently managed at present. There is no linkage between the registry for stroke, TBI and brain tumors in the country.

9. There is a lack of centralized reporting mechanism, to allow streamlined documentation and utilization of epidemiological data on ABI in India. Such mechanisms could potentially enhance consolidation of epidemiological information on ABI from various hospital or population based registries located in different districts or states. It could also help integrate the information from various registries for stroke, brain tumor, TBI and cerebral infections such as encephalitis (especially Japanese encephalitis), meningitis and cerebral malaria. This creates an urgent need for policies and regulation for a centralized information management organization or system in the country that could aid robust epidemiological investigations on ABI.
10. The Documentation of disease related information in most of the hospitals in India is not performed by utilizing a generic method. International classification of diseases (ICD) is a commonly used method in many hospitals for documentation worldwide. However, many hospitals in India do not practice documentation based on ICD. Even in those few hospitals that practice ICD based documentation, there exist significant discrepancies in coding between individuals and hospitals.^[21] Practice of a generic system of paper or computer based documentation of ABI could be made compulsory in government and private hospitals. Health professionals can be trained to start documenting disease related information in a standardized format right from their academic sessions and practice placements.
11. Lack of electronic documentation and dependence on printed records makes the task of documentation and consolidation of existing data on ABI from various hospitals and registries cumbersome. Paper based records are also prone to duplication and human errors, which can be significantly reduced by electronic documentation. In addition, paper based documentation does not allow quick retrieval and analysis of data.^[22] There is a strong potential for this to happen if the existing framework for electronic documentation from national aids control program and revised national tuberculosis control program is utilized to develop a similar system for ABI too.

How do we Proceed Further?

ABI is a heterogeneous health condition encompassing multiple etiologies leading on to some common effects of diverse severities. Understanding the epidemiology of ABI will help evaluate the impact of such a neurologic injury in the community. Translating this understanding into public health practice will not only help in prevention of ABIs but will also help policymakers plan programs and pathways for managing the disability experienced by those affected. As

discussed above, there are multiple challenges that hinder our approach to understanding epidemiology of ABI. Inadequate case definition and case ascertainment, lack of centralized reporting mechanisms and the lack of population based studies are some of the major obstacles.

The authors urge for a radical change in the way epidemiological data on ABI is collected, managed and utilized. Following a standard case definition, using the existing mechanisms such as telemedicine to screen for cases in rural areas and not just limiting studies to cities and urban areas, linking multiple hospital-based registries, initiating a state or nationwide population-based registry, conducting population-based studies that are methodologically robust and introducing centralized and standard reporting mechanisms for ABI could be some of the strategies that will facilitate a thorough investigation into the epidemiology and understanding of ABI, which in turn will help improve policies on management of acquired neurologic diseases. It may also help in facilitating mechanisms to understand and address other health conditions.

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Chapter 3.3

Systematic Review of Educational Interventions for Reducing Disability Following Acquired Brain Injury

Preamble

In order to develop the proposed intervention based on existing evidence, a comprehensive global systematic review of educational interventions for rehabilitation in acquired brain injuries was undertaken. Findings from the review informed the development of an evidence-based rehabilitation intervention for the management of post-stroke disabilities. This review was completed based on the Cochrane guidelines for conducting systematic reviews and it was submitted to the BMC systematic reviews journal. The manuscript was peer reviewed and revised based on the comments from the reviewers and has been re-submitted to the journal. The manuscript of this research paper is included as a chapter in this section.

3.3 A Systematic Review of Educational Interventions for Reducing Disability Following Acquired Brain Injury

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Student	SURESHKUMAR KAMALAKANNAN
Principal Supervisor	PROF GVS MURTHY
Thesis Title	Development and evaluation of a Smartphone-enabled Carer-supported Educational intervention for management of disabilities following stroke in India

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Stage of publication	Submitted

SECTION D – Multi-authored work

<p>For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)</p>	<p>I conceived the study, designed the study, collected the data and analysed it under the guidance of my supervisors Prof GVS Murthy and Dr Hannah Kuper. I took support from the Cochrane Injuries group and Cochrane Stroke group to design the search strategy and run the search in different databases. I took help from one of the co-author to collect, screen, review and analyse the study data. I also wrote the first draft of the manuscript and prepared subsequent revisions with consideration of comments from my supervisors and other co-authors.</p>
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Student Signature: _____

Date: 7/8/2015

Supervisor Signature: _____

Date: 7/8/2015

3.3 A Systematic Review of Educational Interventions for Reducing Disability Following Acquired Brain Injury

Abstract

Background

Acquired brain injury (ABI) is a group of clinical conditions that cause injury to the brain after birth. It often results in disability. Many people with ABI become permanently disabled with profound effects on their quality of life. Educational interventions assist individuals with brain injury, their families and carers to access support services and to make informed decisions regarding their ongoing treatment and care and to manage ABI.

Objective

This review aims to evaluate the effectiveness of educational interventions used in rehabilitation of patients with ABI and their primary caregivers for reducing disability.

Methods

A systematic review of randomised controlled trials on educational interventions for ABI survivors was carried out in compliance with the structured format outlined in the Cochrane Handbook. We included randomised controlled trials (RCTs) of educational interventions for rehabilitation in acquired brain injury. The primary outcome was measures of disability and dependency, and secondary outcomes were measures of quality of life of people with ABI and their carers. Two review authors independently selected trials, extracted data and assessed trial quality.

Main Results

Ten trials that met the eligibility criteria were included in the review with 1,497 ABI patients and 557 primary caregivers. We could not identify any trials from Low and Middle-Income Countries. Available evidence suggests that active, patient-centred, educational interventions reduce the extent of disability, enhance participation and improve quality of life in patients with ABI. Although the differences in treatment effects were statistically significant for these outcomes in the included trials, clinical benefits were relatively small. Provision of educational interventions using workbooks and scheduled telephone contacts appears to be efficient strategies. However, evidence was insufficient to determine the benefits of educational interventions for ADL in patients with ABI. We found no evidence of any beneficial effect of educational interventions on the quality of life of carers.

Conclusion

Available evidence provides a framework and structure for a need-based, patient-centred, multi-disciplinary educational intervention that could be designed and developed for ABI survivors and that could possibly meet the rehabilitation needs of ABI survivors, especially in Low and Middle-Income Countries.

Keywords: Acquired Brain Injury, Brain Injury Rehabilitation, Disability, Educational Intervention, Randomised Controlled Trials, Stroke, Systematic Review, Traumatic Brain Injury.

3.3.1. Background

Acquired Brain Injury (ABI) is brain damage caused by events after birth ¹. ABI can result from traumatic events such as road traffic accidents, falls and violence, in which case it is termed Traumatic Brain Injury (TBI) ². Alternatively, ABI can result from non-traumatic causes, including cerebrovascular accidents (i.e. stroke), infections, vascular malformations and malignancies of the brain ². Individuals with ABI are often affected by a range of sensory-motor, cognitive-perceptual and behavioural impairments ³. These impairments can reduce their ability to independently perform daily activities such as feeding, dressing, grooming, bathing and mobility ⁴. These activity limitations may limit the ability of affected individuals to participate effectively in their family and social roles, leading to disability and reduced quality of life ⁵⁻⁶. The severity of disability depends not only on the impairments that arise from the ABI, but also on the affected individual's environmental (e.g. availability of wheelchair or other assistive devices) and personal factors (e.g. level of education or wealth) ⁷. ABI not only affects individuals, but also their families, who often are the primary caregivers ⁸⁻⁹.

Description of the Intervention

Patient education is a process of enabling individuals to make informed decisions about their personal health-related behaviour ¹⁰. The National Institute of Clinical Excellence (NICE) recommends the provision of information and education as an essential component of service provision for long-term conditions such as ABI ⁹. Educational interventions in brain injury rehabilitation help survivors, their family and carers to access support services and to make informed decisions regarding their ongoing treatment and care, as well as to manage their own condition ¹¹. Organised provision of such client-centred rehabilitation interventions can help patients regain functional independence in their activities of daily living ¹¹.

3.3.2. Objective

The objective of this review was to evaluate the effectiveness of educational interventions used in rehabilitation of patients with ABI and their primary caregivers for reducing disability. Conducting this review was envisaged to assist in designing educational interventions for rehabilitation that are sensitive to the needs of patients and their primary carers. This was particularly needed for Low and Middle-Income Countries, since most available evidence comes from High Income Countries, where more extensive rehabilitation services are available ¹¹.

3.3.3. Methods

The systematic review was prepared in compliance with the structured format outlined in the Cochrane Handbook ¹².

Criteria for Considering Studies for this Review

a. Types of studies

Randomised controlled trials (RCTs)

b. Types of participants

Individuals with ABI of all ages and/or their primary caregivers

c. Types of interventions

Educational interventions specifically aimed at reducing disability and/or facilitating social participation in persons with ABI and their primary carers were included in the review.

We defined an educational intervention for brain injury rehabilitation as a programme that met the following four criteria:

1. Provided by any professional member of the brain injury rehabilitation team (e.g. occupational therapist, physiotherapist, speech language therapist or social worker).

2. Involved active interaction between the intervention provider and the recipient during rehabilitation, rather than a one-off session without further follow-up.
3. Provided support, information and/or management strategies to the person with ABI and/or primary caregiver.
4. Was tailored to the needs of affected individuals and/or their primary caregivers (i.e. including the felt needs of the patients and caregivers in goal setting and treatment)

We included educational interventions irrespective of the participant type (group or individualised) and setting in which they were delivered (hospital-based, home-based or community-based), including telecommunication technologies (e.g. mobile phones). Studies where the educational intervention was administered as part of a multi-component programme were also considered, but only if education was the primary component of the multi-component intervention.

Educational interventions were compared with:

- Usual/Standard care;
- Pharmacological interventions, (e.g. treatments for psychological problems and pain relief)
- Rehabilitation interventions that did not include specific or exclusive educational components (e.g. physiotherapy, occupational therapy, provision of orthotics or assistive devices).
- A combination of any of the above.

d. Types of outcome measures

Primary outcome:

- Disability.
- Activities of daily living.
- Dependency in family and social participation.

Secondary outcome:

- Quality of life of patients with ABI.
- Quality of life of the primary caregivers.

Search Methods for Identification of Studies

a. Electronic searches

The search was carried out in October 2014 using electronic databases. The search was not restricted by date or language. The electronic databases sourced included:

- Cochrane Injuries Group Specialised Register (to latest version);
- Cochrane Stroke Group Specialised Register (to latest version);
- CENTRAL (The Cochrane Library, latest issue);
- MEDLINE/PubMed (1950 to the most recent date available);
- EMBASE (1980 to the most recent date available);
- CINAHL (1982 to the most recent date available);
- PsycINFO (1806 to the most recent date available);
- LILACS
- ISI Web of Science: Science Citation Index Expanded (SCI-EXPANDED) (1970 to the most recent date available);

- ISI Web of Science: Social Science Citation Index Expanded (SCI-EXPANDED) (1970 to the most recent date available);
- ISI Web of Science: Conference Proceedings Citation Index-Science (CPCI-S) (1990 to the most recent date available);
- Clinical trial registers (www.clinicaltrials.gov).
- Controlled trials metaRegister (www.controlled-trials.com).

We based the electronic database searches on the MEDLINE strategy which was adapted, as appropriate, for other databases. The search strategy for MEDLINE database is listed in appendix 2

b. Searching other resources

Trials were also identified through the following:

- From reference lists of review articles and eligible studies;
- By consultation with colleagues;
- By hand searching the most relevant journals (i.e. *Journal of Head Trauma Rehabilitation, Neurological Rehabilitation and Brain Injury*).

Data Collection and Analysis

a. Selection of studies

Two reviewers (SK and LS) independently assessed the titles and abstracts of articles from the search to produce a list of possibly relevant reports. Two reviewers then assessed the full text of these reports to identify eligible trials for the review. Disagreements were resolved by discussion, with recourse to a third reviewer (GVS) if needed.

b. Data extraction and management

Data from the trials included were extracted by one reviewer and independently checked by a second reviewer. The details were extracted from included trials on study methods, participants, intervention and outcomes and were entered into RevMan ¹², a specialised computer program used by Cochrane reviewers to conduct systematic reviews.

c. Assessment of methodological quality in included studies

We assessed the methodological quality of the included trials using the risk of bias assessment tool from the Cochrane Handbook for Systematic Reviews of Intervention ¹².

Assessment was performed using the following checks:

- Random sequence generation (selection bias).
- Allocation concealment (selection bias).
- Blinding of participants and personnel (performance bias).
- Blinding of outcome assessment (detection bias).
- Incomplete outcome data (attrition bias).
- Selective reporting (reporting bias).
- Other possible biases.

We scored each of the following domains as high risk of bias, low risk of bias or unclear risk of bias and reported them in the risk of bias tables.

d. Dealing with missing data

Where clarification on any aspect of a study was required, one of the review authors (SK) contacted the author of the trial.

e. Data synthesis

Data analysis was performed using RevMan. Studies were grouped into broad types of outcomes for data synthesis purposes. We analysed interventions directed at patients separately from those directed at primary caregivers. Interventions in the included trials were highly heterogeneous and tools to evaluate the trial outcomes differed widely. Therefore, a narrative approach was adopted to describe the results of the review, instead of a meta-analysis.

3.3.4. Results

Description of Studies

Characteristics of the included studies are shown in Table 3.3.1.

Results of the Search

Figure 3.3.1 shows the study identification and selection process for the review. We identified 2,271 records through database search and 950 records by searching other sources. Following the screening, 3,001 records were excluded based on titles and abstract and the full text for 78 records were assessed for eligibility. Sixty-eight studies were found to be ineligible and the remaining ten trials that met the eligibility criteria were included in the review.

a. Included studies

The current analysis includes 10 completed trials with 1,497 ABI patients and 557 primary caregivers¹³⁻²². We did not identify any trials from Low and Middle-Income Countries. Of the 10 trials included in the review, four were targeted only towards ABI patients^{13-14, 17, 20}, two involved only the primary carers^{16, 18} and four focussed on both patients and their

primary carers^{15, 19, 21-22}. Two trials included participants with traumatic brain injury (TBI)¹³⁻¹⁴. The majority of the patients in the TBI trials were male, aged 30-35 years. Eight trials included participants with stroke and their primary carers¹⁵⁻²². The majority of the participants in the stroke trials were at least 60 years old and over 60% were male.

Figure 3.3.1: Study identification and selection process for the review

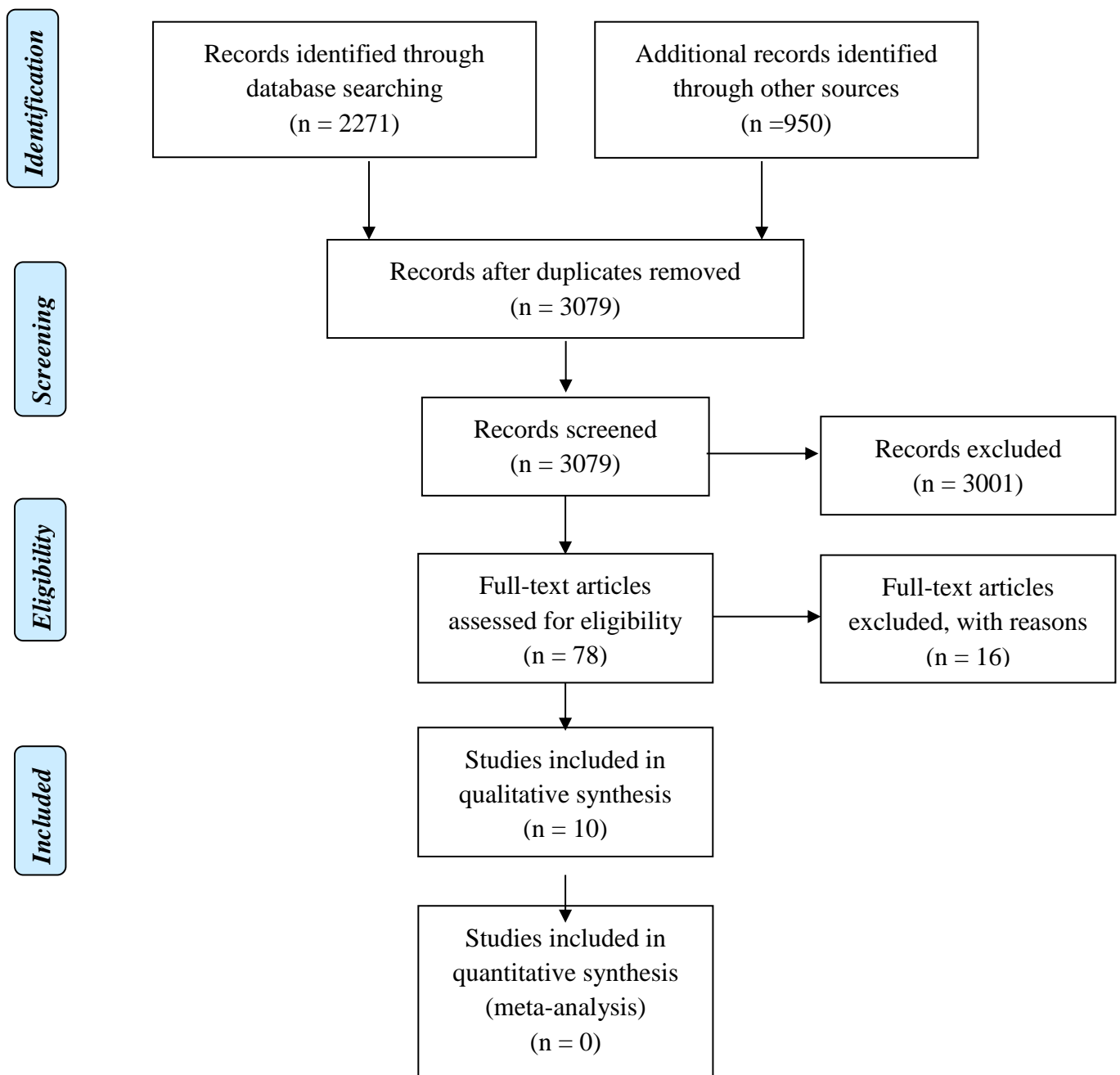


Table 3.3.1: Characteristics of included studies

Study ID	Country	Diagnosis	Participants			Intervention						
			Sample size	Mean age	Sex	Treatment	Theoretical approach	Control	Focus	Setting	Provider	Follow - up
Bell 2005 ¹³	USA	Traumatic brain injury	Total No - 171 Follow-up - 157	Treatment - 34 Control - 37	Male 70-80%	Scheduled telephone intervention	Motivational interviewing	Usual care	Patients	Home	Research care manager	One year
Bell 2008 ¹⁴	USA	Traumatic brain injury	Total No - 366 Follow-up - 313	Treatment - 33 Control - 32	Male 60-65%	Scheduled telephone intervention	Motivational interviewing	Usual care	Patients	Home	Psychologist Sociologist Social Worker	Six months
Clark 2003 ¹⁵	Australia	Stroke	Total No - 68 Follow-up - 62	Treatment - 73 Control - 71	Male 60-65%	Stroke information package and counselling	Family systems theory	Usual care	Patients and carers	Home	Social Worker	Six months
Dahlin 2008 ¹⁶	Sweden	Stroke	Total No - 100 Follow-up - 91	Treatment - 69 Control - 67	Female 75-85%	Stroke Group meetings	Family systems theory	Usual care	Carers	Hospital	Specialist nurses	One year
Desrosiers 2007 ¹⁷	Canada	Stroke	Total No - 62 Follow-up - 56	Treatment - 70 Control - 70	Male 50-55%	Stroke Group meetings	Self-awareness	Discussion - not related to leisure	Patients	Home	Occupational Therapist and Recreational Therapist	Three months

Evans 1988 ¹⁸	USA	Stroke	Total No - 188 Follow-up - 127	Treatment - 49 Control - 50	Female 90%	Lecture, video session, group discussion	Cognitive behavioural approach	Discussion - not related to leisure	Carers	Hospital	Occupational Therapist and Social Worker	One year
Glass 2004 ¹⁹	USA	Stroke	Total No - 291 Follow-up - 265	Treatment - 69 Control - 70	Female 50%	Family meetings	Family systems theory	Standard leaflets	Patients and family	Home	Social Worker Psychologist	Six months
Harwood 2012 ²⁰	New Zealand	Stroke	Total No - 172 Follow-up - 139	Treatment - 61 Control - 61	Male 50-60%	Take Charge Session and workbook	Self- directed rehabilitation	No treatment	Patients	Hospital	Trained Research assistants	One year
Johnston 2007 ²¹	UK	Stroke	Total No - 203 Follow-up - 158	Treatment - 69 Control - 69	Male 60%	Stroke workbook	Self-control	Usual care	Patients and carers	Home	Workbook implementer	Six months
Smith 2004 ²²	UK	Stroke	Total No - 170 Follow-up - 133	Treatment - 75 Control - 74	Female 50%	Stroke recovery programme manual	Previous qualitative work	Stroke Association leaflets	Patients	Hospital	Stroke unit staff	Six months

b. Interventions:

Setting

Four trials were conducted in the USA, two in the U.K and the remainder in Australia, Sweden, New Zealand and Canada. Seven trials were conducted at the patient's home^{13-15, 17, 19-21} and three in a hospital setting^{16, 18, and 22}.

Target Group for Intervention

Educational interventions in eight trials were provided on a one-to-one basis and were provided in groups in two trials^{16, 18}.

Content and Administration

All ten trials included in the review were active educational interventions where there was a purposeful attempt to allow interaction between the information provider and trial participants throughout the treatment plan. Educational interventions in all these trials were administered by a therapist, specialist nurse or social worker. In two trials, the treatment was provided by trained research assistants whose professional qualifications were not reported²⁰⁻²¹.

Two trials included a scheduled telephone-based interaction¹³⁻¹⁴. A qualified psychologist, or sociologist contacted the participants by telephone. The calls consisted of a brief motivational interview, counselling or education. The calls were subject-centred, with the goal of providing information and reassurance on the general course of recovery from TBI. The calls were aimed at helping patients to develop a plan for managing specific symptoms related to TBI. Participants were also given a toll-free number to contact the information provider if

they had questions or needed assistance outside of the scheduled telephone intervention. In three trials,²⁰⁻²² the intervention was provided using educational workbooks. Harwood et al (2012) evaluated a self-directed rehabilitation programme called the 'Take Charge Session' (TCS) which was provided using a booklet²⁰. This intervention helped patients and their carers identify for themselves areas where they could make progress and helped them to set personal goals.

Johnston et al (2007) delivered a workbook to participants, which provided information about stroke and recovery, coping skills and self-management²¹. Task materials (e.g. for goal setting), diary sheets and an audio relaxation cassette tape that described simple body relaxation and breathing exercises were also provided.

Smith et al (2004) provided participants with a stroke recovery manual, which contained information about causation and consequences of stroke, recovery, financial benefits and other services, and included a specific section for carers²². Participants were also invited to attend meetings with members of their multidisciplinary team (doctor, nurse, physiotherapist, and occupational therapist) in order to provide background information about stroke, discuss the patient's progress, answer specific questions and develop shared rehabilitation goals.

Three trials evaluated one-to-one, client-centred educational interventions for ABI patients^{15, 17, 19}. In the trial by Clark et al (2003), stroke information and counselling was provided to stroke patients by a social worker trained in family counselling¹⁵. In another study by Desrosiers et al (2007), the target of the intervention was leisure awareness¹⁷. A recreational therapist was responsible for the intervention and an occupational therapist facilitated leisure participation among the patients. In a third study by Glass et al (2004), a family-systems

approach was used for the intervention, whereby stroke was treated as a crisis for the entire family system ¹⁹. A psychologist or social worker trained in family-systems and cognitive behavioural therapy provided the intervention. When possible, the entire support system (stroke survivor, primary caregiver, additional family and friends, and professional caregivers) was involved in the intervention.

Two trials for carers/spouses of ABI patients used a group educational intervention ^{16, 18}. Dahlin et al (2008) used group meetings held for spouses of stroke patients ¹⁶. Topics for discussion during the meeting included stroke symptoms, occurrence, risk factors, treatment, prevention, personality changes and social aspects. The aim of the intervention was to improve knowledge about stroke and to give spouses the opportunity to discuss their problems related to care giving. The discussion was facilitated by specialist nurses and included spouses of other stroke patients. Evan et al (1988) reported on an intervention where caregivers of stroke patients attended two one-hour educational sessions ¹⁸. The first hour was a lecture, and a videotape entitled "Living with Stroke" was presented by an occupational therapist. The second hour was facilitated by a social worker in order to explain treatment unique to the family's situation and to respond to questions from the carers.

Timing of the Intervention

In three trials, the educational intervention was implemented prior to discharge from hospital ^{16, 18, 22} and, in five trials, within one month after hospital discharge ^{13-15, 19, 21}. In the remaining two trials, one was implemented within three months of stroke ²⁰ and the other within 24 months of stroke ¹⁶.

Outcomes Measured

The studies measured a range of outcomes. Details of these are provided in the 'Characteristics of included studies' (Table 3.3.1) and 'Outcomes and findings from the included studies' (Table 3.3.2).

Assessment of Disability and Dependency in Everyday Life

All ten trials included in the review evaluated the impact on patient functioning in everyday life¹³⁻²². The trials used many different tools for assessing outcomes:

- Five trials evaluated the extent of disability and its impact on functioning^{13-14, 20-22}. These measures included: Disability Rating Scale (DRS)²³⁻²⁴, Glasgow Outcome Scale Extended (GOSE)²⁵⁻²⁶, Functional Status Examination (FSE)²⁷, Observer Assessment of Disability (OAD)²¹, Modified Rankin Scale (MRS)²⁸⁻²⁹, London Handicap scale³⁰ and Head Injury Symptom Checklist (HISCL)¹⁴.
- Eight trials assessed the patient's functional ability to perform basic ADL^{13-16, 19-22} through use of Barthel Index (BI)³¹, Functional Independence Measure (FIM)³²⁻³³ and Frenchay Activities Index (FAI)³⁴.
- Two trials^{20, 22} measured a patient's functional ability to perform advanced instrumental ADL using FAI and BI^{34, 31}.
- Four trials evaluated patient participation in family activities, social activities and leisure^{14-15, 17-18}. Participation measures included Family Assessment Device (FAD)³⁵, leisure performance, Personal Adjustment and Role Skills Scale (PARS)³⁶ and Adelaide Activities Profile (AAP)³⁷.

Assessment of Secondary Outcomes

Five trials evaluated quality of life of the patients^{13, 15-17, 20} and one trial evaluated the quality of life of the carers¹⁵.

c. Excluded studies

Sixteen studies were excluded from the review³⁸⁻⁵³. Seven trials were excluded because the educational intervention was part of a multi-component complex rehabilitation programme where education was not the primary component of interest³⁸⁻⁴⁴. Three studies did not include random allocation procedures and were quasi-experimental⁴⁵⁻⁴⁷. In another three trials, the intervention was not tailored to the needs of the patient or carers⁴⁸⁻⁵⁰. Finally, in two trials, there was no active interaction between the information provider and the patients⁵¹⁻⁵², while another lacked suitable controls⁵³.

d. Risk of bias in included studies

Risk of bias - graph and summary are shown in Figure 3.3.2 and Figure 3.3.3, respectively.

Allocation (selection bias)

Randomisation was clearly concealed in all the ten trials included in the review¹³⁻²². Randomisation was computerised in five trials^{13-15, 17, and 19}, while it was concealed using sealed opaque envelopes in three trials^{16, 21-22}. Among the remaining, allocation was by random number sequence in one¹³ and by minimisation in another¹⁸.

Blinding (performance bias and detection bias)

Blinding of the participants and personnel to treatment assignments was not reported in eight trials^{13-18, 20-21}. Participants and investigators were aware of treatment assignment in one trial¹⁹, while, in another trial, the investigators were aware of the treatment assignment²². Outcome assessment was blinded in nine trials and was not reported in one (Dahlin 2008¹⁶).

Study Size and Completeness of Follow-up

The sample size in the included trials ranged from 62¹⁷ to 366¹⁴. Sample size calculation was reported in five trials^{13-15, 17, 22}. The proportion of patients lost to follow-up in the included trials ranged from 7 %¹⁵ to 22%²¹⁻²². The follow-up assessment was incomplete in one trial²¹.

Method of Analysis

Six trials reported that analyses were conducted based on intention-to-treat principles^{13-14, 19-22}. The intention-to-treat approach was adequately described only in two of these six trials²⁰⁻²¹.

Figure 3.3.2: Risk of bias summary

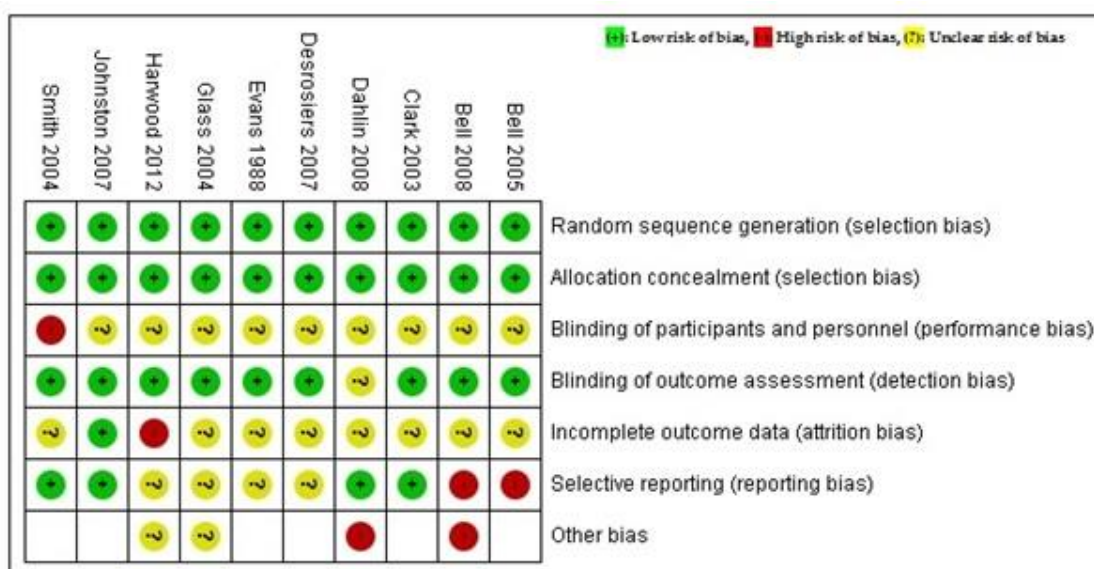
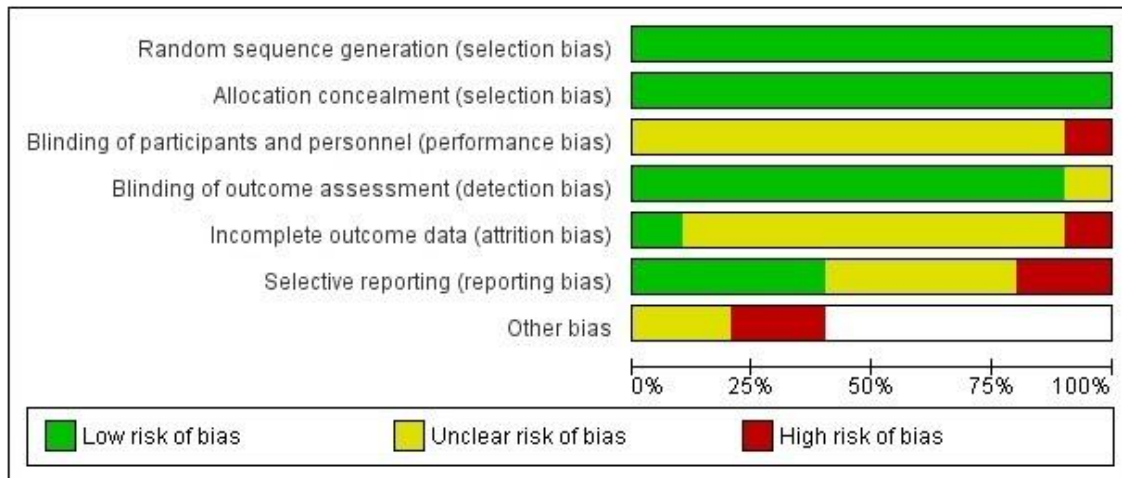


Figure 3.3.3: Risk of bias graph



Other Potential Sources of Bias

Outcome evaluation was done using a single composite test (combining a number of individual outcome measures) rather than a separate evaluation of individual outcome measures in two trials¹³⁻¹⁴. The trial protocol was altered during the course of the study in one trial¹⁴, as the original plan of three trial arms was reduced to two. In one trial²⁰, twelve-month follow-up was incomplete and trial results were available only for 80% of participants in each arm of the trial.

Effects of Interventions

Results are reported separately for patients and carers. We have presented a narrative summary of the results stratified by outcomes, given that the interventions and outcomes were too disparate to allow meta-analysis.

i. Patient outcomes

i.a. Extent of disability in traumatic brain injury patients

Two trials¹³⁻¹⁴ evaluated the extent of disability as an outcome. Both these trials evaluated a tele-education method that provided scheduled telephone-based education for patients with traumatic brain injury. Bell (2005)¹³ evaluated the extent of disability among moderate to severe TBI patients using the Glasgow Outcome Scale - Extended (GOSE)²⁵⁻²⁶. Participants in the tele-education group had lower mean scores of disability following the intervention than the control group during the 12-month follow-up (mean difference=0.40, 95% CI, -0.05 to 0.84), though this did not reach statistical significance (P = 0.08).

Bell (2008) used the Head Injury Symptom Checklist (HISCL) for evaluating disability among mild TBI patients at six months post-intervention¹⁴. The study used a composite evaluation method to measure clinical outcomes. Participants assigned to receive scheduled telephone-based education had fewer post-traumatic symptoms and fewer functional difficulties compared to the control group at six-month follow-up. The difference in mean composite scores (post-traumatic symptoms) between the treatment and control groups was 6.6 (1.2, 2.0), P = 0.02.

i.b. Extent of disability in stroke patients

Three stroke trials evaluated the extent of disability among stroke patients²⁰⁻²². Harwood (2012) assessed the extent of disability using the Modified Rankin Score (MRS) at 12 months post-treatment²⁰. Participants in the treatment group were less dependent on others for ADL compared to the control group. The estimated main effect (MRS > 2) for the treatment group compared to the control group, expressed as an odds ratio, was 0.42 (0.20 to 0.89) with P = 0.02.

Johnston (2007) used an Observer Assessed Disability (OAD) tool to measure outcomes at six months post-treatment ²¹. At follow-up, participants in the intervention group were less disabled and were less dependent on others for their everyday living compared to the control group. Mean OAD scores and standard deviation at six-month follow-up for the intervention group was -0.09 (SD 1.00) and 0.09 (SD 0.99) for the control group, $P = 0.02$. Smith (2004) evaluated disability using the London Handicap Scale ³⁰, but did not find a statistically significant difference between the intervention and control group ²².

i.c. Activities of daily living (ADL) in traumatic brain injury patients

Two trials evaluated ¹³⁻¹⁴ ADL in patients with TBI. Bell (2005) evaluated ADL using the Functional Independence Measure (FIM) scale ¹³. The authors reported that the ADL scores were significantly higher in the intervention group ($p = 0.02$), but did not present the mean values. Bell (2008) evaluated patient functioning using a questionnaire and found no significant differences between the trial arms ¹⁴.

i.d. Activities of daily living (ADL) in stroke patients

Six trials ^{15-16, 19-22} evaluated ADL in stroke patients. Harwood (2012) ²⁰ and Smith (2004) ²² measured instrumental ADL using the Frenchay Activities Index and the remaining trials used Barthel Index.

Clark (2003) measured ADL using Barthel Index at six-month follow-up in patients who received a stroke information pack and home visits by the social workers (intervention) compared with those who did not (control) ¹⁵. The trial reported better functional recovery among patients in the treatment group compared to the control group. The mean Barthel Index scores and standard deviation at six-month follow-up for the treatment group was 18.7

(SD 2.0) and, for the control group, it was 17.4 (SD 3.9), $P < 0.05$. The remaining five trials found no significant difference between the treatment and control group in this outcome.

i.e. Participation

Three trials^{14-15, 17} measured the effects of educational intervention on participation outcomes. Bell (2008) reported that mild TBI patients who received telephone-based education had significantly better outcomes in terms of return to work ($P = 0.02$) and leisure ($P = 0.03$) compared to the control group¹⁴.

Clark (2003) evaluated participation using the AAP and FAD for stroke participants at six-month follow-up¹⁵. Participants in the treatment group experienced better social recovery as measured by domestic chores ($P < 0.05$), household maintenance ($P < 0.01$) and social activity ($P < 0.05$) domains of AAP. The mean FAD score was also significantly better in the treatment group (1.77, SD 0.12) than in the control (1.96, SD 0.27) $P < 0.001$ at six-month follow-up.

Desrosiers (2007) measured participation of stroke patients in leisure activities¹⁷. The trial evaluated treatment effects using the number of minutes spent on active or passive leisure and number of leisure activities that a patient performed post-intervention. Participants in the treatment group engaged in more distinct active leisure activities ($P = 0.002$) and for a longer duration ($P = 0.01$) than controls. Patients in the control group participated more in passive leisure when compared to the treatment group.

i.f. Quality of life

Five trials^{13, 15-17, 20} evaluated the effects of educational intervention on quality of life of patients with ABI. Bell (2005) evaluated quality of life using the Euro Quality of Life (EuroQoL) and Perceived Quality of Life (PQOL) scale at 12-month follow-up¹³. TBI patients in the treatment group had better quality of life scores when compared to the control group (mean difference) EuroQOL: 0.10 (0.02 to 0.19), $P = 0.02$; PQOL: 8.8 (1.7 to 15.9), $P = 0.02$). Harwood (2012) used a Health Related Quality of Life (HRQOL) tool to evaluate the treatment effects at 12-month follow-up. Participants in the treatment group had significant improvement in the physical component summary of the HRQOL scale ($P = 0.004$).

Three stroke trials¹⁵⁻¹⁷ found no significant difference between the intervention and control groups in the quality of life outcome. Clark (2003) used the visual analogue scale component of the Euro QOL for assessment¹⁵. Dahlin (2008) evaluated quality of life using the SF- 36 reported by the carer for the patient¹⁶. Desrosiers (2007) measured the effects of intervention on quality of life through the Stroke Adapted Sickness Impact Profile (SA-SIP30) at three-month follow-up¹⁷. Two trials that evaluated quality of life of patients at 12 months post-treatment detected significant difference in the treatment group^{13, 20}, whilst two trials evaluated this outcome only at three or six- month follow-up^{15, 17}.

ii. Carer outcomes

ii.a. Quality of life

Only one trial¹⁵ assessed the effect of the educational intervention on carer quality of life and found no evidence of an effect.

Table-3.3.2: Outcomes and findings from the included studies

No	Studies	Subjects	Group comparison	Primary outcome	Assessment points	Intervention	Control	Findings	Statistical significance
1	Harwood 2012 ²⁰	Stroke	Intervention: Take Charge of self session (n=46) Control: written materials about stroke (n=39)	Extent of disability measured by Modified Rankin Scale (Dichotomised).	One year	N = 38 MRS>2 =11	N = 31 MRS>2 =12	Odds ratio (95% CI) 0.42 (0.20 – 0.89)	P = 0.02
2	Johnston 2007 ²¹	Stroke	Intervention: workbook for stroke recovery using a workbook implementer (n=103) Control: written materials about stroke (n=100)	Observer assessed disability	Six months	Mean = + 0.19 S.D = 1.01	Mean = - 0.17 S.D = 0.95	F - value 5.61	P = 0.01
3	Smith 2004 ²²	Stroke	Intervention: stroke recovery programme + Manual (n=66) Control: standard information handout about stroke (n=63)	London Handicap Scale	Six months	Mean = 57.33 S.D = 13.76	Mean = 53.9 S.D = 14.29	Mean Difference (95%CI) 3.43 (-1.45 - 8.31)	P = 0.16

4	Desrosiers 2004 ¹⁷	Stroke	Intervention: home-based Stroke Leisure education Programme (n= 33) Control: standard follow-up home visit (n=29)	minutes of leisure activity per day, number of leisure activities	Three months	No of Leisure: Pre-treatment 8.3 (+/- 2.9) Post-treatment 10.6 (+/- 3.3) Duration of Leisure: Pre-treatment 41.7 (+/- 17.1) Post-treatment 58.9 (+/- 20.4)	No of Leisure: Pre-treatment 8.3 (+/- 2.9) Post-treatment 10.6 (+/- 3.3) Duration of Leisure: Pre-treatment 41.7 (+/- 17.1) Post-treatment 58.9 (+/- 20.4)	Mean Difference (95%CI) No of Leisure: 2.9 (1.1 – 4.8) Duration of Leisure: 14.0 (3.2 – 24.9)	No of Leisure: P = 0.002 Duration of Leisure: P = 0.01
5	Clark 2003 ¹⁵	Stroke	Intervention: home-based stroke education with social worker counselling visits (n= 32) Control: standard care (n=30)	Family functioning (Family Assessment Device - FAD) Adelaide Activities Profile - AAP	Six months	Mean (SD) FAD - 1.77 (0.12) AAP : Domestic chores 35.2 (15.8) Household maintenance 33.8 (11.8) Service to others 48.9 (18.5) Social activities 50.4 (8.2)	Mean (SD) FAD - 1.96 (0.27) AAP : Domestic chores 29.5 (21.5) Household maintenance 31.1 (18.6) Service to others 44.3 (15.2) Social activities 38.9 (7.9)	Mean Difference (95%CI) FAD: F = 7.45 AAP : Domestic chores F = 6.52 Household maintenance F = 7.15 Service to others F = 0.82 Social activities F = 4.05	FAD: P = 0.001 AAP : Domestic Chores P = 6.52 Household Maintenance P = 7.15 Service to others P = 0.82 Social activities P = 4.05

6	Glass 2004 ¹⁹	Stroke	Intervention: targeted group session for the patient and his/her family (n=146) Control: workbook on stroke (n=145)	Barthel Index	Three and six months	Mean (SD) Three months: 87.1 (14.2). Six months: 89.5 (14.1)	Mean (SD) Three months: 85.4 (17.2). Six months: 86.5 (18.2)	Logistic regression at six months 1.6	P = 0.31
7	Evans 1988 ¹⁸	Stroke	Intervention: education and counselling for carers of stroke survivors (n= 64) Control: standard care (n=63)	Stroke care Information test - SCIT and various other psychological assessments	Six months and one year	Mean (SD) Six months : 23.7 (5.3). One year: 23.0 (5.5)	Mean (SD) Six months: 15.8 (5.3). One year: 14.2 (4.8)	Mean Difference Six months : F = 38.6. One year: F = 38.6	P < 0.001
8	Dahlin 2008 ¹⁶	Stroke	Spouses of stroke survivors Intervention :six group meetings (n = 50) control (n = 50)	Level of knowledge about stroke and various other psychological assessments	Six months and one year	Mean (SD) Six months: 17.71 (5.55). One year: 22.61 (5.35)	Mean (SD) Six months: 16.58 (5.18). One year: 20.73 (5.02)	Mean Difference was assessed	P = 0.04
9	Bell 2005 ¹³	TBI	Intervention: scheduled telephone follow-up (n=85) Control: standard care (n=86)	A composite outcome (FIM, DRS, CIQ, NFI, FSE, GOS-E, SF-36, BSI, EuroQOL, PQOL)	One year	Not reported	Not reported	Not reported	P = 0.002

10	Bell 2008 ¹⁴	TBI	Intervention: scheduled telephone follow-up (n=171) Control: standard care (n=195)	A composite outcome measure for post-traumatic symptoms and general health	Six months	Mean Post-traumatic symptoms - 52.6 General health - 50.5	Mean Post-traumatic symptoms - 46 General health - 49	Mean Difference (95%CI) Post-traumatic symptoms 6.6 (1.2, 12.0) General health - 1.5 (-2.2, 5.2)	Post traumatic symptoms P = 0.01 General health P = 0.41
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3.3.5. Discussion

This review explored the effectiveness of educational interventions for rehabilitation in patients with ABI. We restricted the review to educational interventions that included active participation of patient/carer with reinforcement and support from the intervention providers. After screening about 3,000 published studies, we identified 10 eligible RCTs. The methodological quality of the included trials was generally poor. None of the trials were conducted in a Low and Middle-Income Country setting and there were no trials for non-traumatic causes of ABI other than stroke. A meta-analysis was not carried out due to differences in the types of interventions and outcome measures used in the included trials.

Summary of Main Results

Available evidence suggests that active patient-centred educational interventions reduce the extent of disability, enhance participation and improve quality of life in patients with ABI. Although the differences in treatment effects were statistically significant for these outcomes in the included trials, clinical benefits were relatively small. Provision of educational interventions using workbooks and scheduled telephone contacts appear to be efficient strategies. However, evidence was inadequate to determine the benefits of educational interventions for ADL in patients with ABI. We found no evidence of any beneficial effect of educational interventions on the quality of life of carers.

Methodological Limitations of Included Studies

There were several methodological limitations in the included trials. Sample size in most of the trials included in the review was small. Although studies were powered with adequate number of participants at the outset, loss to follow-up ranged from 7 % to 22 %. Analysis based on intention to treat principles was either not reported or inadequately described in many trials.

In one trial ¹⁶, excessive attention to the control group provided by the health professionals may have contributed to the lack of difference in treatment effect between the intervention and control groups. Not all participants attended all group sessions in the intervention group of this trial.

A higher than expected proportion of patients who were randomised had sustained minor strokes with no or few functional deficits in one trial ¹⁹. Although this trial intended to include patients with severe stroke, many trial participants had high functional scores on the Barthel Index at baseline and throughout follow-up. This would have created a ceiling effect during the study analysis.

Blinding of participants and personnel to treatment assignment was not reported in eight trials and was absent in two trials. Lack of blinding participants and personnel is expected to contaminate treatment effects and provide biased results in almost all of the included trials given the use of patient and carer-reported outcome measures.

Many trials were conducted in a single centre; therefore, generalisability of findings from these trials to other settings is limited. Outcome evaluation using a single composite test (combining a number of individual outcome measures) was carried out in two trials ¹³⁻¹⁴. Although this type of outcome evaluation increases the power to detect treatment effects, they suffer from difficulty with interpretation and for understanding the magnitude of treatment effect. In addition, these two trials did not provide complete information about the trial results in their publication, further complicating our ability to interpret the findings from these trials.

The methodological limitations among the included trials could have substantial bearing on the validity of the results of this systematic review. Therefore, the results of the review should be interpreted with care.

Agreements and Disagreements with Other Studies or Reviews

A previous review of educational interventions for changing provider behaviour to improve quality of care reported that educational approaches involving active learning were more likely to be effective than passive approaches ⁵⁴. Meta-analysis of strategies for patient teaching has also demonstrated significant effects associated with the use of multiple strategies rather than a single technique ⁵⁵. This review had defined educational intervention that conforms to the findings from the above mentioned reviews of Thesis (1995) and Grimshaw (2001)

A review by Smith et al (2008) on provision of information for stroke patients and their carers demonstrated positive effects on patient knowledge and satisfaction ⁵⁶. It also provided evidence for strategies that actively involve patients and that include planned follow-up. As proposed by Smith et al (2008), this review intended to look at active educational interventions that involved multiple strategies, including reinforcements and structured follow-up for reducing disability and enhancing participation in patients with ABI. Overall, findings from this review are consistent with these previous studies and reviews.

Implications for Practice

Available evidence supports the provision of educational intervention for patients with ABI and their families. Patient-centred educational interventions with consistent reinforcement and support can reduce patient disability, promote participation in social activities and improve their quality of life. Findings from the studies included in the review also suggest that educational

interventions addressing the needs of patients and their families with multiple strategies, such as telecommunication, group meetings and the use of workbooks, are more beneficial than passive information provision where there is no active interaction between the intervention providers and the patients.

Implications for Research

Future research on educational interventions for brain injury rehabilitation should focus on designing a multi-centre study with an adequate sample size and robust follow-up strategies. This could help with generalising the study findings to communities where the burden of brain injury is prominent. Although it is hard to blind participants and personnel to treatment assignment in complex rehabilitation interventions, researchers should make every effort to ensure that lack of blinding does not affect study results. Future studies should also consider evaluating functional outcomes using objective methods and standardised tools and outcome measures, rather than subjective self-reported measures to allow meta-analysis and comparison between studies.

Implication for LMICs

Much of the evidence, especially in the form of randomised controlled trials (RCT) comes from HICs. Although RCTs are considered to be an important source of evidence because they minimise bias⁵⁷, it is highly challenging to conduct such controlled trials of rehabilitation strategies in LMICs⁵⁷. Many rehabilitation trials, even from HICs, have been underpowered and suffer from other severe methodological flaws¹¹. Given the complexity of rehabilitation interventions, it is also difficult to identify the active component(s) of the intervention that influences specific treatment outcomes⁵⁶. Lack of good quality evidence for stroke rehabilitation in HICs poses problems in the adaptation of rehabilitation strategies for use in

LMICs. The dearth of evidence also makes it difficult to develop cost-effective educational interventions to enhance the self-management of post-stroke disability, especially in a resource-constrained setting like India.

This review did not find any RCTs on educational interventions for ABI survivors in LMICs. Although there were methodological limitations, available evidence from HICs does provide a framework and structure for a need-based, patient-centred, multi-disciplinary educational intervention that could be designed and developed to meet the rehabilitation needs of ABI survivors in LMICs. Future studies could also consider the methodological limitations identified among the studies included in this review and design a methodologically robust trial to establish the effectiveness of educational interventions for ABI survivors.

4.3.6. Conclusion

Available evidence from this review provides a framework and structure for a need-based, patient-centred, multi-disciplinary educational intervention that could be designed and developed for ABI survivors. Development and validation of rehabilitation interventions based on the findings from this review could possibly meet the rehabilitation needs of ABI survivors, especially in Low and Middle-Income Countries.

Chapter 4

**Rehabilitation Needs of Stroke Survivors after
Discharge from Hospital in India.**

Preamble

In addition to the evidence from the systematic review of educational interventions for Acquired Brain injuries, development of the proposed intervention was also informed by the actual experience of the stroke survivors, their carers and the health professionals providing stroke services in Chennai India. This exercise facilitated the development of the intervention that is culturally-specific and relevant to the rehabilitation needs of the stroke survivors living in the community.

Preliminary findings of this needs assessment study was presented at the World Stroke Congress last year and the presentation abstract was published in the International Journal of Stroke. The study was completed and submitted as a research paper to the Archives of Physical Medicine and Rehabilitation. This accepted version of the research paper is published online within the article in press section of the journal. The accepted manuscript of this research paper is included as a chapter.

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RESEARCH PAPER COVER SHEET

PLEASE NOTE THAT A COVER SHEET MUST BE COMPLETED FOR EACH RESEARCH PAPER INCLUDED IN A THESIS.

SECTION A – Student Details

Student	SURESHKUMAR KAMALAKANNAN
Principal Supervisor	PROF GVS MURTHY
Thesis Title	Development and evaluation of a Smartphone-enabled Carer-supported Educational intervention for management of disabilities following stroke in India

If the Research Paper has previously been published please complete Section B. If not please move to Section C

SECTION B – Paper already published

Where was the work published?	Archives of Physical Medicine and Rehabilitation		
When was the work published?	September 2016		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion	Not Applicable		
Have you retained the copyright for the work?	Yes	Was the work subject to academic peer review?	Yes

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SECTION C – Prepared for publication, but not yet published

Where is the work intended to be published?	Already Published
Please list the paper's authors in the intended authorship order:	1. K Sureshkumar, 2. G V S Murthy, 3. Audrey Prost, 4. N Subbulakshmy, 5. Hira B Pant 6. C Naveen, 7. Shifalika Goenka 8. Hannah Kuper
Stage of publication	Choose an item.

SECTION D – Multi-authored work

For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)

I conceived the study, designed the study, collected data and analysed study data under the guidance of my supervisors Prof GVS Murthy and Dr Hannah Kuper. I took support from my supervisors and three other co-authors to complete quantitative and qualitative data analysis. I also wrote the first draft of the manuscript and prepared subsequent revisions with consideration of comments from my supervisors and other co-authors.

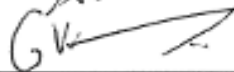
Student Signature: _____



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7/8/2015

Supervisor Signature: _____



Date: _____

7/8/2015



ORIGINAL RESEARCH

Rehabilitation Needs of Stroke Survivors After Discharge From Hospital in India

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Abstract

Objective: To assess the rehabilitation needs of stroke survivors in Chennai, India, after discharge from the hospital.

Design: Mixed-methods research design.

Setting: Home-based.

Participants: Stroke survivors (n=50; mean age \pm SD, 58.9 \pm 10.5y) and primary caregivers of these stroke survivors (n=50; mean age \pm SD, 43.1 \pm 11.8y) took part in the quantitative survey. A subsample of stroke survivors (n=12), primary caregivers (n=10), and health care professionals (n=8) took part in the qualitative in-depth interviews.

Interventions: Not applicable.

Main Outcome Measure: Rehabilitation needs after hospital discharge.

Results: About 82% of the needs expressed by stroke survivors and 92% of the needs expressed by caregivers indicated that they had a substantial need for information. The proportion of financial needs reported by the stroke survivors and the caregivers was 70% and 75%, respectively. The qualitative data revealed major gaps in access to stroke rehabilitation services. Service providers identified availability and affordability of services as key problems. Stroke survivors and their caregivers identified lack of information about stroke as major barriers to accessibility of stroke rehabilitation services. Caregivers expressed a tremendous need for support to manage family dynamics.

Conclusions: The study highlights a considerable unmet need for poststroke rehabilitation services. Given the lack of rehabilitation resources in India, developing an accessible, innovative, patient-centered, culturally sensitive rehabilitation intervention is of public health importance. It is crucial for low- and middle-income countries like India to develop technology-driven stroke rehabilitation strategies to meet the growing rehabilitation needs of stroke survivors.

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Stroke is the second leading cause of mortality worldwide¹ and is associated with a wide variety of sensorimotor, cognitive perceptual, and behavioral impairments.² These poststroke impairments might limit the ability of stroke survivors to independently perform their activities of daily living.³ Consequently,

they might also restrict effective participation in family and social roles.⁴ A significant proportion of stroke survivors therefore become disabled, with profound effects on their quality of life.⁵

India, like other low- and middle-income countries, is experiencing a stroke epidemic.⁶ During the past 2 decades, the prevalence of stroke in India is estimated to range from 84 to 262 per 100,000 population in rural areas to 334 to 424 per 100,000 population in urban areas. Stroke in India therefore poses a major

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public health challenge, given the disabling nature of the condition and the growing magnitude of disability.

There is a dearth of information about the rehabilitation needs of persons with disabilities, especially after stroke, in India where persons with disabilities in general encounter several barriers to access rehabilitation services.⁷⁻⁹ One would expect the needs of stroke survivors in India to be substantial and diverse, given the range of disabilities caused by stroke and the existing barriers to access services.

This situation warrants an understanding of the needs of the stroke survivors living in a country like India, since this would assist in developing innovative rehabilitation interventions that are accessible, patient-centered, and culturally sensitive. It could also facilitate the efficient use of locally available resources to meet the rehabilitation needs of stroke survivors in this context. Therefore, this study was undertaken to assess the various kinds of rehabilitation needs among the stroke survivors, and the factors contributing to these needs, using a mixed-methods approach. The primary objective of this study was to assess the rehabilitation needs of stroke survivors in Chennai, India, after discharge from the hospital.

Methods

This formative study used (1) a structured questionnaire with a purposively selected sample of 50 stroke survivors and 50 caregivers; and (2) qualitative in-depth interviews with a subsample of 12 stroke survivors, 10 primary caregivers looking after them, and 8 health care professionals involved in providing stroke rehabilitation services.

Study setting

The study was conducted in T.S. Srinivasan Institute of Neurological Sciences—The Voluntary Health Services Multispecialty Hospital and Research Center, Chennai, Tamil Nadu, India, between August 2013 and December 2013. Formal ethics approval was obtained from Institutional Ethics committees.

Participant inclusion and exclusion criteria

Persons were eligible for inclusion in the study if they met the following criteria: (1) they were adults; (2) they had recently received a diagnosis of stroke (within the previous 6wk) as defined by the World Health Organization¹⁰; (3) the stroke was of minor or moderate severity (ie, score of 1–15 according to the National Institutes of Health [NIH] Stroke Scale¹¹⁻¹³); (4) they had been discharged from the hospital; and (5) they were residing at home with a primary caregiver. Stroke survivors were excluded if any of the following criteria were present: (1) severe communication problems (scoring >1 in dysarthria and best language component of the NIH Stroke Scale¹¹⁻¹³); (2) severe cognitive difficulties (scoring >1 in orientation, executive function, inattention, and language components of the NIH Stroke Scale components for cognition¹¹⁻¹³); (3) severe comorbidities (severe psychiatric illness, hearing loss, vision loss); (4) severe stroke (ie, scoring >15 according to the NIH Stroke Scale¹¹⁻¹³); and (5) inability to provide consent autonomously.

List of abbreviations:

NIH National Institutes of Health

Quantitative methods

The survey was conducted using a structured needs assessment questionnaire, specifically developed for the study. Its purpose was to identify the rehabilitation needs of stroke survivors and the barriers and facilitators encountered by them in accessing stroke rehabilitation services. Separate questionnaire schedules were developed for stroke survivors and their primary caregivers based on the World Health Organization Disability Assessment Schedule¹⁴ as well as tools used in previous studies.¹⁵

Statistical analysis was completed using STATA 13.^a The frequency of each kind of response was calculated separately, and an aggregate score was obtained for each domain. The aggregate score for each kind of response in a domain (ie, the aggregate score of “small,” “moderate,” “large,” and “very large” need) was then converted into proportions of “total needs” for each of these domains.

Qualitative methods

Separate topic guides with open-ended questions and prompts were developed for stroke survivors, their primary caregivers, and health professionals. The in-depth interview process ended when a saturation point was reached. The purpose of the in-depth interviews was to gain a comprehensive understanding of the experiences of the stroke survivors and their primary caregivers in relation to accessing stroke rehabilitation services and their rehabilitation needs after stroke. All the interviews were audio-recorded with consent from the respondents.

The qualitative data were transcribed verbatim and translated into English. Transcribed data were then analyzed using the framework approach.¹⁶

Results

Demographics

Using hospital records, we identified 99 stroke survivors. Thirteen (13.1%) of them did not survive after hospital discharge. Twenty-one (21.2%) could not be contacted, and 15 (15.1%) resided far from the hospital. In total, 50 stroke survivors and 50 primary caregivers linked to them were selected to participate in the study. Almost all participants were living within a 20- to 30-km radius of the hospital. The demographic and clinical characteristics of the participants are shown in [tables 1](#) and [2](#).

Quantitative results

All study participants reported needs in every domain incorporated in the questionnaire. None of the participants mentioned not having any rehabilitation needs. [Figures 1](#) and [2](#) show the proportion of total needs for each domain reported by the stroke survivors and caregivers. The most important need for both stroke survivors and primary caregivers was related to information about “stroke and stroke rehabilitation service.” About 82% of the needs expressed by stroke survivors and about 92% of the needs expressed by caregivers in this domain indicated that they had a substantial need for information. Financial needs and support was the second most important domain for participants. The proportion of needs reported by the stroke survivors and the caregivers in this domain was nearly 70% and 75%, respectively.

Table 1 Demographic and clinical characteristics of stroke survivors

Characteristics	Male Participants	Female Participants	All Participants	P for Male-Female Differences
Sex	33 (66)	17 (34)	50 (100)	NA
Age (y)	57.2±10.2	61.9±10.6	58.9±10.5	.13
Education: primary or higher	24 (73)	12 (70)	36 (72)	.88
Marital status: married	33 (100)	17 (100)	50 (100)	1.00
Working before stroke	30 (91)	4 (24)	34 (68)	.00*
Currently working in the same job	6 (18)	0 (0)	6 (12)	.00*
First-ever stroke	33 (100)	15 (88)	48 (96)	.04*
Stroke type				
Ischemic	31 (94)	16 (94)	47 (94)	.88
Hemorrhagic	2 (6)	1 (6)	3 (6)	1.00
Stroke severity				
Minor	11 (33)	5 (29)	16 (32)	.77
Moderate	22 (67)	12 (71)	34 (68)	.77
Affected side				
Right	14 (42)	10 (59)	24 (48)	.28
Left	18 (55)	5 (30)	23 (46)	.09
Both	1 (3)	2 (11)	3 (6)	.26
Receiving physiotherapy	3 (9)	4 (24)	7 (14)	.17
Use of mobility aids	7 (21)	4 (24)	11 (22)	.87

NOTE. Values are n (%), mean ± SD, or as otherwise indicated.

Abbreviation: NA, not applicable.

* $P < .05$.

The other important rehabilitation needs prioritized by both the stroke survivors and their caregivers were those related to the management of symptoms after stroke, rehabilitation services, and support in the community. The proportion of needs expressed by the stroke survivors and caregivers in these domains approximately ranged from 55% to 65%. Caregivers expressed that they need to be looked after by other family members and the community while they provided care and support to the stroke survivors. Sixty-eight percent of the responses from caregivers were related to this domain. About 50% of the needs expressed by the study participants were related to the stroke survivors' psychological needs and needs related to transfers and mobility. Both stroke survivors and their caregivers felt that stroke survivors require assistance to deal with their poststroke psychological issues and mobility problems.

The needs expressed by both the stroke survivors and caregivers for the rest of the domains were less than 50%. There was no statistically significant difference between the needs expressed by stroke survivors and their caregivers in any of these domains.

Qualitative results

Results from the qualitative in-depth interviews agreed with and complemented findings from the quantitative survey.

Gaps in access to stroke rehabilitation services

Findings from the in-depth interviews helped investigators in deriving a framework (fig 3) for understanding the gaps in access to stroke rehabilitation services and provides reasons for the stroke survivors to have substantial rehabilitation needs. Greater details about the barriers to accessibility of stroke rehabilitation services are provided in supplemental table S1 (available online only at <http://www.archives-pmr.org/>).

Availability of rehabilitation services

There was a wide gap between the demand and supply of stroke rehabilitation services in Chennai. Findings from the study reveal that there was an acute insufficiency of rehabilitation services for people with disabilities in general, even in a major metropolitan city such as Chennai. Rehabilitation services to assist people with

Table 2 Demographic characteristics of the primary caregivers of stroke survivors

Characteristics	Male Participants	Female Participants	All Participants	P for Male-Female Differences
Sex	12 (24)	38 (76)	50 (100)	NA
Age (y)	37.9±14.0	44.7±10.7	43.1±11.8	.08
Education: primary school or higher	12 (100)	28 (73.7)	40 (80)	.04*
Employed	11 (91.6)	14 (36.8)	25 (50)	.00*
Previous training for caregiving	0 (0)	0 (0)	0 (0)	1.00

NOTE. Values are n (%), mean ± SD, or as otherwise indicated.

Abbreviation: NA, not applicable.

* $P < .05$.

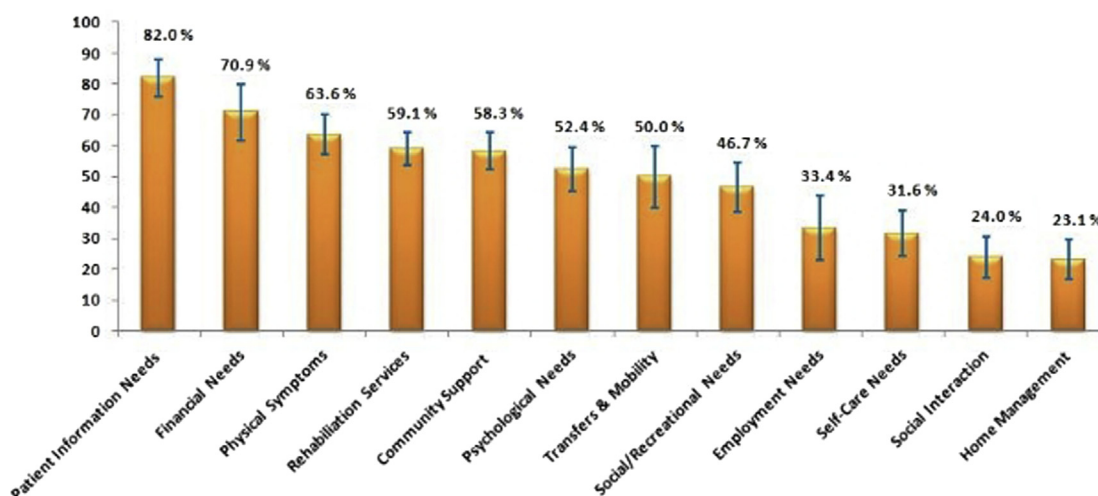


Fig 1 Rehabilitation needs of the stroke survivors for various functional domains as reported by the stroke survivors. Frequency of responses for various functional domains expressed in percentage.

disabilities were hardly available to the neediest. Health providers interviewed acknowledged that there were only 2 well-known neurorehabilitation centers in the entire state of Tamil Nadu in India. An experienced physiatrist said, “The concept of rehabilitation itself is like quite new to India, I think...we are not used to... this process of rehabilitation; Here and there this has been done, but on very low scale and insignificantly.”

None of the participants reached a hospital for their stroke straight away. It took a minimum of 2 days for the respondents to find a hospital that could provide treatment and rehabilitation. Most of them reached the hospitals by word of mouth from friends and neighbors. When health professionals were asked about the efforts from the government or private health sector to address this issue, another physiatrist with expertise in evidence-based brain injury rehabilitation said, “I don’t think anything substantial that’s being done either in terms of primary prevention or treatment. You

don’t have a all in one stroke treatment and rehabilitation unit as you have in Scandinavian and European countries. So definitely, we are lagging behind in a big big way.”

Stroke survivors and caregivers reported that the quality of available services was not adequate. In general, many respondents were not satisfied with the services obtained in the hospitals where they were treated for their stroke. A health provider himself explained, “In the country, rehabilitation is almost equal to physiotherapy and physiotherapy is almost equal to passive movements of upper limbs and lower limbs. We don’t have a goal-oriented, time-bound program that would aim at functional improvement.”

Affordability of services

There is only 1 government-managed general rehabilitation center for persons with disabilities in the entire state, and it is located in Chennai. Although rehabilitation services are free in this facility,

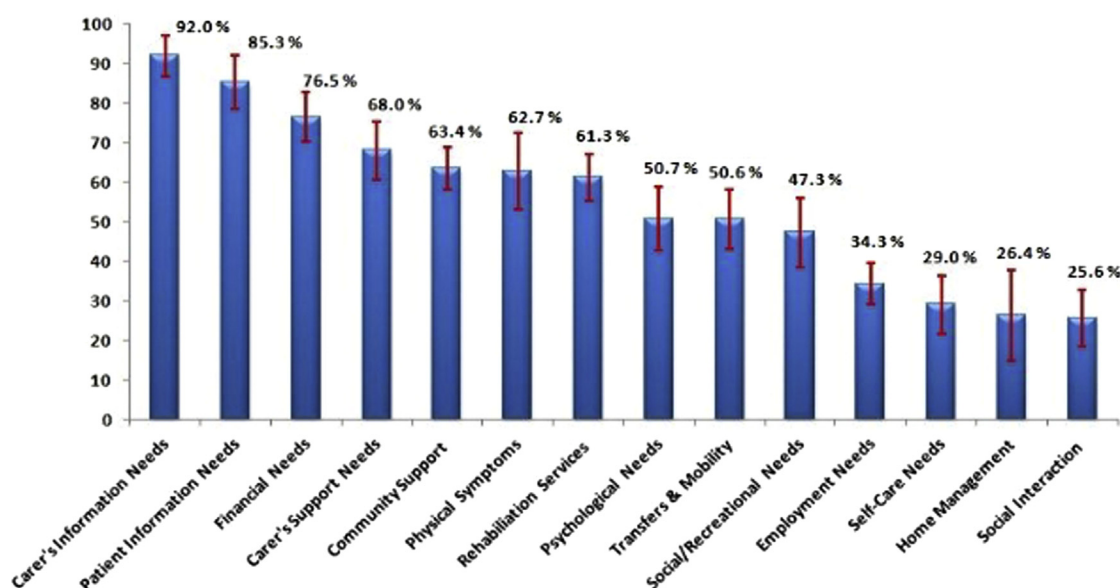


Fig 2 Rehabilitation needs of the stroke survivors for various functional domains as reported by the caregivers. Frequency of responses for various functional domains expressed in percentage.

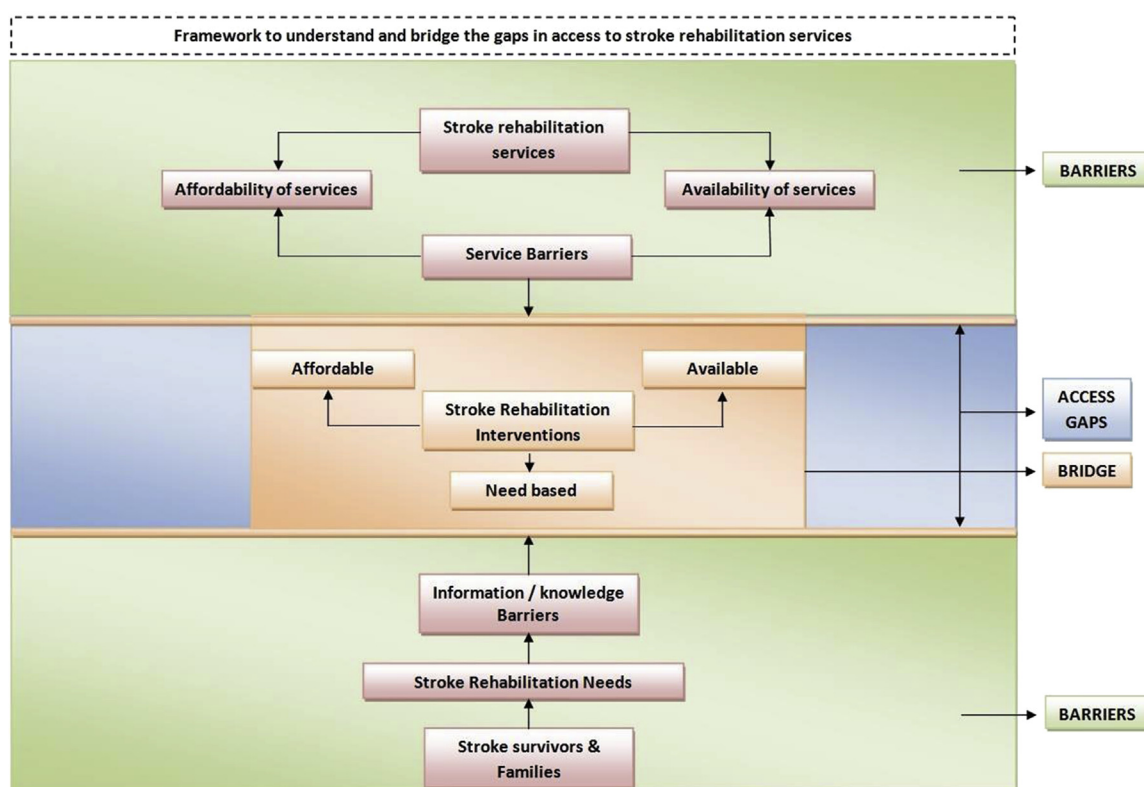


Fig 3 Framework to understand and bridge the gaps in access to stroke rehabilitation services.

people had to travel long distances and pay for the travel themselves to access these free services. Most often, people who could not afford to travel long distances even within the city and those who did not have the time or the money sought rehabilitation services from the nearest physiotherapy clinic. However, even this undisciplined therapy service was not affordable to many of the interviewed respondents. This was especially the case in poor families, when the breadwinner of the family was affected by stroke, or both. One caregiver said, "Only with his earning, our family is running. We don't have any other support and it is very difficult to be in this situation—what to do? I am clueless. I have to go for work. I should try and do any work that is available. It's just what God has in store for me."

Given the unexpected onset of stroke, respondents said they were not prepared and often unable to organize resources for managing the problems of individuals affected by stroke within their family. Priority was given to immediate medical treatment, and most funds were spent for acute stroke treatment, which was usually expensive. Subsequently, the families ran out of funds to continue postacute rehabilitation services. An occupational therapist explained, "If a patient has a stroke, he has to take up all the medical expenditures on his own. When accessing a particular hospital they will be admitted in the ICU, and other medical care, for that itself they pay 1 or 2 lakhs, when it comes to rehabilitation, they may not be able to afford. Then once the money has dried out, compliance reduces and they don't complete what they started."

Availability and affordability of stroke rehabilitation services were the major service level barriers that existed in the study context. Most people who could not afford rehabilitation services

remained at home, not being appropriately looked after by family. Poststroke complications and severity of disability increase when stroke survivors do not receive appropriate rehabilitation services.⁴ Subsequently, this increases their rehabilitation needs. Given the lack of availability and affordability of stroke rehabilitation services, the rehabilitation needs of the stroke survivors were largely unmet, and the demand for available and affordable stroke rehabilitation services becomes substantial.

Information and knowledge barriers

Lack of information and knowledge about stroke and stroke rehabilitation services was identified as a major barrier to accessibility that existed among the stroke survivors and their family. Lack of awareness about stroke, stroke-related disability, and rehabilitation often concealed the overt demand for rehabilitation services. None of the stroke survivors, caregivers, and family members interviewed were able to identify the warning signs of stroke and seek immediate treatment for it. Most of them felt that the symptoms of stroke would resolve after rest or sleep. Most stroke survivors and the caregivers were not able to pinpoint a cause. When a stroke survivor was asked about the cause for his stroke, he said, "The doctors used to tell me frequently to check my blood pressure, but I used to tell him, 'That and all will come and go sir.' But now only, I am realizing that how BP affects; nobody told. I don't know that I will get stroke if I drink."

When stroke survivors and their family were asked whether they received any information about stroke from the health care providers at hospitals where they were treated, most said that they had not.

Many stroke survivors and caregivers did not know there was a rehabilitation center located within the hospital where they

received treatment for their stroke. Most also felt that the onus is on the stroke survivors and their family to gain information about the problem and on ways to manage it. A young stroke survivor expressed, “No ... so far no one has given me information or given me any treatment...The situation is—Only I must do something for myself to improve.”

Health providers felt that ignorance about stroke and the inability to accept stroke-related disability among the stroke survivors and their family were major problems in communicating with them. One health provider said, “The difficulty is always in explaining the reality to the individual and family members that uh... the neurological function that is lost cannot be remediated by anymore intervention; that’s the felt need for most of the patients. Nobody comes here saying that I have hemiplegia, make me walk with the quadruped; they say I am not able to use upper limb, set it right. That’s the biggest challenge that we face.”

From the perspective of the service receiver, findings from the qualitative interviews suggest that lack of awareness and knowledge about stroke and the process of stroke recovery among stroke survivors and their families was an important barrier to bridging the gaps in access to stroke rehabilitation services. This was an important reason for the stroke survivors and their families to demand more information about stroke and stroke-related services (supplemental table S2, available online only at <http://www.archives-pmr.org/>).

Support for the caregivers

Support needs of caregivers came up as a major concern for the caregivers themselves and also for the stroke survivors. Caregivers and family members reported considerable change in their family roles and responsibilities when stroke occurred in a family member. Caregivers required appropriate support to physically and mentally manage these abrupt changes in roles and family dynamics (supplemental table S3, available online only at <http://www.archives-pmr.org/>).

Discussion

This study identified a widespread need for rehabilitation services among stroke survivors and their caregivers in India. Information needs and financial support needs were the 2 major domains expressed by the participants. The information and support needs of caregivers were much greater compared to those of the stroke survivors. This explains the compelling need to equip caregivers as much as possible so that they can fully support the stroke survivors.

Findings from the qualitative interviews also revealed major gaps in access to stroke rehabilitation services in the study context. Overcoming barriers to the provision of stroke rehabilitation services, especially availability and affordability, appears to be essential to meet the rehabilitation needs of stroke survivors. However, the information and knowledge needs of stroke survivors and their caregivers and families should also not be underestimated while attempting to develop strategies to meet the rehabilitation needs of stroke survivors. Unless stroke survivors are informed about their need for rehabilitation and the services available for it, appropriate utilization of any kind of stroke services cannot be expected.

The demographic characteristics of the stroke survivors in this study were very similar to those in previous epidemiologic studies on stroke conducted in India.¹⁷ To our knowledge, this is the first needs assessment study of this sort carried out in India. Indeed, the authors were able to identify only 2 other such studies^{18,19} carried

out in low- and middle-income countries. These studies^{18,19} also found that information was the topmost priority for the stroke survivors. Although the context is very different, findings in our study were similar to those in similar studies^{15,20-24} conducted in high-income countries.

This study has 2 major strengths. First, it used a mixed-methods design, which enabled us to obtain a richer understanding of rehabilitation needs.²² Second, the assessment was not restricted to stroke survivors alone; caregivers and health care providers were also included. These 2 strategies helped us gain a better understanding of the key factors that contribute to the gaps in accessibility to stroke rehabilitation services.

Study limitations

The study also has 2 major limitations. First, participants were all recruited from a single hospital, which limits the generalizability of our findings. Second, the sample size for the quantitative needs assessment was small, given that there was only 1 hospital that provided permission for recruitment. Similar studies in the future could involve more recruitment centers and include rural areas with poorer access to health services.

Conclusions

Our study shows that there is a substantial unmet need for post-stroke rehabilitation services in Chennai, India. Lack of awareness about stroke and of ways to manage stroke-related disabilities appears to be the primary reason for this. The financial implication of providing therapeutic care and support for stroke survivors becomes an additional burden to both stroke survivors and their families. Given the lack of resources for rehabilitation in India, developing an innovative, multidisciplinary, patient-centered, culturally sensitive rehabilitation intervention is of high public health importance. This could help bridge the gap in accessibility and potentially meet the rehabilitation needs of the stroke survivors in India. Results from this needs assessment had contributed significantly toward the development of a smartphone-enabled caregiver-supported educational intervention for management of disabilities after stroke in India. The detailed description of the intervention can be found elsewhere.²⁵

Supplier

a. STATA 13; StataCorp LP.

Keywords

Health services research; India; Needs assessment; Rehabilitation; Stroke

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Supplemental Table S1 Barriers to accessing stroke rehabilitation services

Contributing Factors	Mechanism by Which the Barrier Causes Inaccessibility	Coping Strategy	Policy Implications
Access to patient transportation to transfer patient to hospital and/or therapy centers	<p>Government ambulance services are very minimal and available only for emergency purposes. Government ambulance services take patients only to the nearest government hospital, which they and their families might not prefer.</p> <p>Private emergency ambulance services and other transport facilities are expensive.</p> <p>Auto rickshaws might not be the preferred mode of transport if patients cannot sit.</p>	Individuals prefer to hire a taxi for transportation, or an auto rickshaw if the patient can sit, and travel to the nearest health facility.	Need for emergency/nonemergency ambulance services that would allow patients to be taken to the nearest health facility that offers stroke treatment and rehabilitation services
Access to hospitals during the acute phase of stroke	<p>Dedicated acute stroke units do not exist in most government and private multispecialty hospitals.</p> <p>Intensive care units for managing acute stroke are situated only in the tertiary hospitals of major cities.</p>	Given the emergency situation, family members usually pay these charges. If they don't have sufficient funds, they will borrow money or sell some of their valuables for treatment.	Provision of acute stroke services in the nearest government primary health centers
Access to treatment during the acute phase of stroke	<p>Admission and bed charges in intensive care units are usually expensive.</p> <p>Professional fees, specialist fees, therapy fees, and fees for using other devices such as pressure mattresses and vital monitors in the intensive care unit are usually expensive and based on the patient's medical condition.</p>	Some caregivers in the family might request the patient to be seen in the general ward itself.	Provision of government health insurance schemes that would cover the cost of acute stroke treatment
Access to investigation, such as computed tomography scan and other tests	<p>Investigation charges for computed tomography scan, magnetic resonance imaging, and special blood tests are usually expensive. Even in a government tertiary hospital where these facilities are readily available, there are charges for such investigations.</p> <p>Investigation facilities might not be available in the same hospital. Patients will often have to travel to the nearest diagnostic facility and come back to the hospital with the investigation report.</p> <p>The administrative processes involved in getting the investigations done in a government tertiary hospital are cumbersome.</p>	<p>Family members usually pay these charges. If they don't have funds, they will borrow money or sell some of their valuables for treatment.</p> <p>Some patients and families skip the investigations and go back to their home. They only come back when they have money for the investigations.</p>	<p>Incorporating basic investigation and diagnostic facilities within private multispecialty hospitals</p> <p>Waiving the charges for investigations and diagnosis in government hospitals</p> <p>Streamlining the administrative processes and reducing administrative delays to ensure patient compliance</p>

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Supplemental Table S1 (continued)

Contributing Factors	Mechanism by Which the Barrier Causes Inaccessibility	Coping Strategy	Policy Implications
Access to medicines and other drugs	Most of the medicines and drugs prescribed by the doctors in private hospitals are usually not available in government pharmacies.	Stroke survivors prefer to get the prescribed medicines from private pharmacies in/near the hospital paying for it.	Ensuring that the prescribed medicines for stroke treatment are available in most of the government and private pharmacies in both urban and rural pharmacies
	Individuals have to pay for the medicines prescribed by doctors in private hospitals.	Stroke survivors with minor stroke usually manage to travel (which they pay for) to a government hospital to get these medicines for free.	Prescriptions for certain medicines/drugs can be provided by medical officers in the government primary health centers, which can then be taken to government tertiary hospital pharmacies.
	Some of the drugs prescribed are available only in pharmacies near the hospital within cities, and may not be available in rural pharmacies.	Relatives usually get these medicines for the patient from pharmacies.	
	Some prescribed medicines are available for free from government pharmacies, but patients require a prescription from a doctor in a government tertiary hospital.		Provision of essential drugs for stroke treatment in primary health centers—making it available
	The administrative processes involved in getting the medicines from a government tertiary hospital are cumbersome.		Streamlining the administrative processes and reducing administrative delays to ensure patient compliance
	The government pharmacies are located in government tertiary hospitals in major cities. Stroke survivors have to travel in person to collect these free drugs and medicines.		Waiving the charges for drugs and medicines for stroke treatment through insurance coverage
Access to therapy and rehabilitation services during postacute phase	Individuals have to make travel arrangements and fund their travel to get these medicines.		
	Professional fees for every specialist, such as physiotherapist, occupational therapist, speech therapist, and psychologist, who meets the stroke survivors and their family. Specialist consultation fees for neurologists, therapy fees (on an hourly basis), and fees for using therapy devices such as ultrasound and electrotherapy are usually expensive.	Family members usually pay these charges. If they don't have funds, they will borrow money or sell some of their valuables for treatment. Some might request the patient to be seen in the general ward itself.	Provision of government health insurance schemes that would cover the cost of stroke rehabilitation and therapy services
Access to appliances and orthotics	Orthotics and rehabilitation appliances such as wheelchairs, crutches, braces, and positioning supports are not readily available.	Most of the stroke survivors do not know about the devices and appliances that can prevent disability and promote participation.	Increasing the availability of orthotics and appliances for stroke rehabilitation in major hospitals and pharmacies
	There are very few centers for producing these devices, and appliances are located in major cities. Hence they are usually expensive.	Given the cost, stroke survivors have to manage their problems/disability without these orthotics and appliances.	Developing infrastructure for manufacturing orthotics and rehabilitation appliances through government health facilities and pharmacies (in-house orthotic units)

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Supplemental Table S1 (*continued*)

Contributing Factors	Mechanism by Which the Barrier Causes Inaccessibility	Coping Strategy	Policy Implications
	Therapists who are aware of the orthotic manufacturers and appliances for stroke rehabilitation usually prescribe these. Many do not.		Manufacturing different kinds of orthotics and appliances for physical rehabilitation. Not just mobility or ambulatory aids.
	Most available orthotics and appliances promote walking and mobility.		Mainstreaming the supply of orthotics and rehabilitation appliances through government health facilities and pharmacies
	Appliances for assisting a stroke survivor with everyday activities, such as brushing, bathing, or toileting, are not available.		
	There is a fee for specialists to visit the patient and take measurements to make some of these devices, or for the patient to travel to the place where these devices are manufactured.		Waiving the charges for orthotics and appliances through insurance coverage.
	Limited supplies of orthotics and appliances are available in the government rehabilitation center (which is the only center for the entire state, situated in Chennai) at affordable prices.		
	Most of these appliances are prefabricated and, hence, might not have the comfort, fit, and function specific to the needs of the stroke survivor.		Provision of guidelines for prescription of orthotics and appliances
	Assessment for fit, comfort, and function of the orthotics; advice on their appropriate use; and the wearing regimen and schedules are not usually available.		
Access to long-term therapy services after the acute stroke phase	Fully-fledged comprehensive stroke rehabilitation services are rarely available to stroke survivors. There are only 2 or 3 such centers available for the entire state.	Having paid for the hospital, therapy and treatment during the acute phase of stroke, stroke survivors and families usually run out of funds to continue therapy services for their stroke-related disabilities.	Development and strengthening of rehabilitation systems, including manpower, infrastructure, financial allocation, policies, information systems, and supplies
	There is only 1 government rehabilitation center, situated in Chennai, for the entire state, with very minimal facilities for the provision of physical rehabilitation services in general.	Family members observe and understand some of the therapeutic exercises provided by the hospital physiotherapist during the hospital stay and become the therapists for stroke survivors.	
	Rehabilitation services available in hospitals and local clinics, and home visits by therapists (physiotherapy) are very expensive.		Mainstreaming the provision of rehabilitation services, along with health care services

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Supplemental Table S1 (*continued*)

Contributing Factors	Mechanism by Which the Barrier Causes Inaccessibility	Coping Strategy	Policy Implications
	Stroke survivors and caregivers have to travel to the rehabilitation center every day to avail themselves of these services, which adds to the cost of treatment.		Promoting organized systems of provision of care and support for individuals affected by stroke
	Home visits by physiotherapists are based on the availability and convenience of the therapists.		Increasing the availability of government-led rehabilitation services (free). Waiving the cost of services through insurance coverage.
	Community-based rehabilitation services for persons with disability generally are not available to those most in need of these services and who cannot afford to pay for them.		
	Hospitals do not have any follow-up pathways for patients who have been treated for stroke in their hospital.		

Supplemental Table S2 Information needs of stroke survivors and their families

Contributing Factors	Mechanism by Which the Factors Escalate the Needs	Common Practice	Implication for Providers
1. Lack of awareness about the risk factors for stroke	Poor control and management of modifiable risk factors for stroke, including hypertension, diabetes, lack of physical activity, obesity, excessive consumption of tobacco and alcohol that can lead to the recurrence of stroke among those who have already suffered one	Affected individuals and families believe that taking the drugs prescribed by doctors will resolve problems and do not think that lifestyle modifications are required.	Provision of detailed information to affected individuals and their families about modifiable and nonmodifiable risk factors for stroke and the ways to control or manage their exposure to them
2. Lack of awareness about the warning signs of stroke	Individuals and families do not identify or recognize the warning signs of stroke, thereby delaying the process of acute stroke treatment and care, which, in turn, could worsen the brain damage caused by a stroke.	Affected individuals and families realize that a stroke has occurred only after the symptoms have worsened; before then, it was considered as general body fatigue, fever, or tiredness.	Provision of information or a mass awareness campaign to the individuals affected and their families about the warning signs of stroke to identify and initiate early treatment
3. Lack of awareness about the golden hours for treatment	There is delay in identifying the occurrence of stroke. This identification happens only when the patient is taken to a tertiary hospital. Early identification and management of stroke could limit brain damage and life-threatening situations for the stroke survivor.	Family members identify some kind of illness and weakness and take the patient to a nearest local clinic. Based on the advice from the doctor in the local clinic, the family members decide whether the individual affected should be taken to a tertiary hospital or can be managed back at home with the drugs recommended by the doctor at the clinic.	Doctors in the clinic and hospitals should be able to identify stroke based on history and examination and refer the individual affected to the nearest tertiary care hospital (if treatment cannot be provided in their hospital) as soon as possible. Since affected individuals have a tendency to go back home if they are feeling better, they should be advised about the golden hours of treatment for stroke and should be encouraged to seek treatment promptly.
4. Lack of awareness about places where appropriate stroke treatment and rehabilitation is available	Based on the family's/individual's values, beliefs, health-seeking behavior, previous knowledge about stroke and the financial situation, a decision is made about where to seek treatment of stroke. However, the decision often leads stroke survivors to visit a minimum of 2 or 3 hospitals for treatment when they have a stroke for the first time. Stroke survivors and their families usually seek treatment at hospitals that can "cure" the problem, according to their beliefs. In doing so, their funds dry up by the time they understand where they can receive the most appropriate services. Many choose to seek nonbiomedical forms of	"Hospital shopping" is a common practice. People shop for hospitals and therapies that might have a "cure" for their stroke. Friends and family provide advice about various nonbiomedical treatments for stroke, such as siddha, Ayurveda, and traditional healing practices.	Stroke treatment and rehabilitation service providers (government and private) could inform the public or individuals affected about the importance of appropriate treatment and rehabilitation after stroke, during their acute hospital treatment and recovery, through their health care providers.
5. Lack of awareness about treatment for stroke		In most rural areas, people seek the help of traditional healers.	They could also conduct stroke awareness campaigns about their services through various communication media and create awareness about appropriate services for stroke among the public.
6. Lack of awareness about rehabilitation after stroke		In some urban areas people also seek traditional healing, siddha, and Ayurvedic treatment, believing that these can "cure" stroke.	

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Supplemental Table S2 (*continued*)

Contributing Factors	Mechanism by Which the Factors Escalate the Needs	Common Practice	Implication for Providers
7. Lack of awareness about recovery after stroke	<p>treatment and care (eg, traditional healing, siddha) in search of a cure, rather than seeking biomedical treatment at an appropriate time. This delay in treatment and rehabilitation increases the severity of poststroke disability and the stroke survivor's dependency on others to perform their day-to-day activities.</p> <p>Understanding and accepting key facts about stroke and stroke-related disability is a major concern for most stroke survivors and their families. They invest money and seek various kinds of treatment to cure stroke. There is a strong expectation that the individuals affected will resume their role and routine as usual after any kind of treatment or therapy, but, when it does not happen, the stroke survivors and their families are in despair.</p>	<p>Many stroke survivors discontinue therapy or other treatments—even medication—and stay at home. They become dependent on other people for engaging in their previous family, social, and work roles. Some stroke survivors become completely dependent on their family, and they may or may not receive appropriate care and support. Especially because of the delayed treatment resulting from hospital shopping, the survivors' poststroke condition tends to be poor and, therefore, the level of dependency is high. This also increases the financial burden borne by the family.</p>	<p>Providers could initiate community-based rehabilitation programs, even if only for patients who come to their hospital for stroke treatment. Active (stroke survivors visit hospital) and passive follow-ups (providers visit stroke survivors) of stroke survivors and their families in the form of support groups, home visits, day clinics, and <i>melas</i> (get-together) could promote better understanding about the recovery process and life after stroke among stroke survivors and their families.</p>

Supplemental Table S3 Support needs of stroke survivors

Contributing Factors	Mechanism by Which the Factors Escalate the Needs	Common Practice	Implication for Providers
Change in family dynamics	Role changes and role reversals in the family are very common when a family member is affected by stroke. Sometimes, the breadwinner has to stop working and support the stroke survivor and other members of the family. Sometimes, the one who was supporting the children and the breadwinner has to start work and earn money. Sometimes, 1 person has to manage many roles, supporting the stroke survivor, family, or children and also earning money for the family.	In a nuclear family, if there is only 1 person to provide support (eg, husband or wife), this person takes over all roles and performs these as far as he/she can (role reversals and role change). In a joint family, other family members share various roles to support both the stroke survivors and the family (role sharing)	Providers can counsel the family members and caregivers and help them prepare for a change in family dynamics.
Availability of the caregivers	If there is only 1 person to take over the role of the stroke survivor and also to support him/her, it becomes very difficult for that person to provide good care and support to the stroke survivor. The family usually moves into a crisis situation until other family members or friends come forward for support. If more than 1 person is available to support, the women (wife, daughter) in the family usually take care of the stroke survivor. Men often assist in hospital follow-ups and also support the family financially. Absence of clarity in one's new role leads to role clashes. For example, a woman might find it difficult to transfer an obese patient to wash them or assist in shifting them from one place to another.	It becomes a substantial burden for the caregiver to manage various different roles effectively. Over a period of time, he/she may become depressed and physically frail. Role clashes and family disputes are very common in this situation. In addition to the problems caused by stroke, affected individuals bear the additional burden of role clashes and family disputes.	Providers could inform the family members about the possibilities of role changes and discuss ways to effectively manage crises and family disputes.
Willingness of the caregivers to engage and support	Caregivers with very little willingness, interest, or motivation to support the stroke survivor do not provide appropriate care and support. The stroke survivor might then experience various stroke-related complications.	Deformities and contractures are very common among stroke survivors who are not positioned well. Pressure sores are common if affected individuals are not mobilized at regular intervals.	Providers can empower caregivers by informing, engaging and training them in various aspects of support and care for the stroke survivor and his/her family during the period of acute stroke hospitalization.
Time constraints	Caregivers sometimes do not have time to manage their own roles, take on an additional role, and support the stroke survivor. Support to the stroke survivor becomes possible only when the caregivers are free from their usual roles.	Most often, expected support is either delayed or not provided. For example, stroke survivors might not receive their medications on time. Sometimes, the caregivers skip over the exercise sessions for the stroke survivors.	

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Supplemental Table S3 (continued)

Contributing Factors	Mechanism by Which the Factors Escalate the Needs	Common Practice	Implication for Providers
Financial constraints	If the stroke survivor was the only earning member of the family, it becomes very difficult for caregivers to meet the financial needs of the family and meet the rehabilitation needs of the stroke survivor.	Money is borrowed or property and jewels are pledged for managing the family and supporting the treatment and rehabilitation expenses for the stroke survivor and the family.	Providers should have an appropriate therapeutic justification (clinical reason) for the services provided to the stroke survivor. Delaying the rehabilitation process and charging unreasonably for treatment should be avoided.
	If caregivers take over the role of the breadwinner, they might not be able to generate an income for the family in the same way that the previous breadwinner did.	There are many tradeoffs in the usual family expenditure in order to support the stroke survivor.	Providers can engage families and stroke survivors in setting achievable goals during their stay for treatment and rehabilitation. This might reduce the cost of therapy and treatment charges.
	Sometimes, the earning member of the family finds it difficult to continue paying for the medical and rehabilitation services for the stroke survivor.	Rehabilitation services for the stroke survivor are discontinued at some point in time.	
Values, beliefs and health seeking behaviors	Values, beliefs, and health-seeking behaviors of the caregivers related to stroke rehabilitation and treatment strongly influence the level of support given to stroke survivors. If caregivers feel that traditional practices could help the affected individual, then the physical rehabilitation for stroke is completely ignored.	Most often, stroke survivors do not have any say in the decision made about their treatment by the caregivers. They trust their family and caregiver decisions and explore various treatment options without having any clarity about the decision made.	Providers could inform and explain in detail the various options available for treatment of stroke, their purposes, and the pros and cons of these treatment options.
Caregivers' awareness about stroke	The caregivers' awareness and understanding about stroke affect the ways in which support needs are identified and provided.	Lack of awareness among the caregivers about stroke is usually one of the most common reasons for the delay in provision of appropriate treatment and care for the stroke survivor.	Providers could educate the caregivers about stroke and the appropriate management of poststroke disability.
Knowledge about caring and supporting a stroke survivor	Lack of knowledge about the exact ways of providing care and support to a stroke survivor affect the postacute prognosis (recovery) of the stroke survivor. This results in poststroke complications such as pressure sores, tightness, contractures, and deformities of the affected side of the body.	Caregivers are ignorant about the advantages of positioning, exercises, use of pillows and devices for supporting the affected hands and legs of the stroke survivor, and engagement of the affected individual in daily tasks.	Information about basic, home-based techniques to care and support the stroke survivor could be provided to the caregivers.
Sex	Female caregivers are usually involved in supporting the stroke survivor with their personal care. But in many situations, female caregivers are dependent on a male caregiver for shifting, lifting, and transporting the stroke survivor. The routine support for personal care of the stroke survivor becomes inconsistent and not as expected by the stroke survivor.	Most stroke survivors prefer a male caregiver for mobilizing them to perform personal care tasks. Until then, they manage their personal care on the bed itself (with bedpan, urinal, sponge bath, and a setup environment kept within the reach of the stroke survivor).	Irrespective of the sex and age of the stroke survivor, providers should involve the stroke survivor, primary caregiver, and key members of the family while sharing any treatment plans and advice for the stroke survivor. Providers should be cognizant about the implications of the stroke survivor's sex and age when helping the family make decisions about treatment and rehabilitation goals.

(continued on next page)

Supplemental Table S3 (*continued*)

Contributing Factors	Mechanism by Which the Factors Escalate the Needs	Common Practice	Implication for Providers
Age	Male caregivers are usually involved in helping the stroke survivor with hospital visits, therapy visits, medicine management, and home management activities. They are usually not available (being at work or managing outdoor activities) most of the times when they are required. This is when the female caregiver finds it difficult to move or mobilize the stroke survivor.	Female stroke survivors usually feel shy about seeking help from a male caregiver for their personal care tasks.	
	Female caregivers are usually less involved in decision-making about the treatment and care of stroke survivors, with male caregivers making most of the decisions. This limits the amount of information and knowledge required to make appropriate decisions for the stroke survivor in the family.	Female caregivers and stroke survivors are usually informed about the decision made by the male member of the family. Most often, they don't raise any questions or concerns or make suggestions about the decision, especially if they are not the breadwinners of the family.	
	Female stroke survivors are not usually involved in making decisions about their treatment. They are only informed about the decision. This phenomenon is reversed for male stroke survivors. This reflects the meager amount of consideration given to the felt needs of the female stroke survivors.		
	In many families, care and support provided to the stroke survivors is indirectly proportional to their age. Young stroke survivors receive substantially more support because they are young and have the capacity to earn or provide support to the family in the future. More elderly stroke survivors do not receive sufficient support.	Many elderly stroke survivors are supported by a paid helper who might not know them very well, or not as well as other members of the family. Alternatively, some elderly stroke survivors are moved to old-age homes where some support services are readily available.	

Chapter 5

‘Care for Stroke’: a Web-based, Smartphone-enabled Educational Intervention for Management of Physical Disabilities Following Stroke.

Preamble

Evidence from the systematic reviews and the rehabilitation needs assessment study described earlier, informed the development of an evidence-based, Smartphone-enabled educational intervention that is culturally-specific and relevant to the needs of the stroke survivors. Development of the intervention was very systematic. Results from the literature reviews and needs assessment study was presented to an expert group to decide on the best content for the intervention. Recommendations from the expert group served as a guideline for the development of the intervention.

To our knowledge, this is the first ever evidence-based mhealth intervention for management of disabilities following stroke. The detailed description of the intervention was published in BMJ innovations 2015. The published paper is presented as chapter 5.

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PLEASE NOTE THAT A COVER SHEET MUST BE COMPLETED FOR EACH RESEARCH PAPER INCLUDED IN A THESIS.

SECTION A – Student Details

Student	SURESHKUMAR KAMALAKANNAN
Principal Supervisor	PROF GVS MURTHY
Thesis Title	Development and evaluation of a Smartphone-enabled Carer-supported Educational intervention for management of disabilities following stroke in India

If the Research Paper has previously been published please complete Section B, if not please move to Section C

SECTION B – Paper already published

Where was the work published?	BMJ Innovations		
When was the work published?	July 2015		
If the work was published prior to registration for your research degree, give a brief rationale for its inclusion	Not Applicable		
Have you retained the copyright for the work?*	Yes	Was the work subject to academic peer review?	Yes

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Where is the work intended to be published?	Not Applicable
Please list the paper's authors in the intended authorship order:	1. K Sureshkumar, 2. G V S Murthy, 3. Suresh Munuswamy, 4. Shifalika Goenka, 5. Hannah Kuper
Stage of publication	Choose an item.

SECTION D – Multi-authored work

<p>For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)</p>	<p>I conceived, designed the study and developed the intervention under the guidance of my supervisors Prof GVS Murthy and Dr Hannah Kuper. I took support from one of the co-author and a team of software consultants to design the web-based application. I developed the content framework with the help of a expert committee consisting of a team of multi-disciplinary stroke rehabilitation experts. I took help from media professionals (videographers and movie editors) to digitize the content of the intervention. I wrote the script for the intervention contents and directed the entire intervention for digitization. I did the editing and sequencing of the intervention videos during digitization. I gave the voice over for the entire intervention. I acted as the therapist for the intervention. I also wrote the first draft of the manuscript and prepared subsequent revisions with consideration of comments from my supervisors and other co-authors.</p>
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Student Signature: _____

Date: _____

Supervisor Signature: _____

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ORIGINAL ARTICLE

'Care for Stroke', a web-based, smartphone-enabled educational intervention for management of physical disabilities following stroke: feasibility in the Indian context

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ABSTRACT

Introduction Stroke rehabilitation is a process targeted towards restoration or maintenance of the physical, mental, intellectual and social abilities of an individual affected by stroke. Unlike high-income countries, the resources for stroke rehabilitation are very limited in many low-income and middle-income countries (LMICs). Provision of cost-effective, post-stroke multidisciplinary rehabilitation services for the stroke survivors therefore becomes crucial to address the unmet needs and growing magnitude of disability experienced by the stroke survivors in LMICs. In order to meet the growing need for post-stroke rehabilitation services in India, we developed a web-based Smartphone-enabled educational intervention for management of physical disabilities following a stroke.

Methods On the basis of the findings from the rehabilitation needs assessment study, guidance from the expert group and available evidence from systematic reviews, the framework of the intervention content was designed. Web-based application designing and development by Professional application developers were subsequently undertaken.

Results The application is called 'Care for Stroke'. It is a web-based educational intervention for management of physical disabilities following a stroke. This intervention is developed for use by the Stroke survivors who have any kind of rehabilitation needs to independently participate in his/her family and social roles.

Discussion 'Care for stroke' is an innovative intervention which could be tested not just for its

feasibility and acceptability but also for its clinical and cost-effectiveness through rigorously designed, randomised clinical trials. It is very important to test this intervention in LMICs where the rehabilitation and information needs of the stroke survivors seem to be substantial and largely unmet.

BACKGROUND

Stroke rehabilitation is a process targeted towards restoration or maintenance of the physical, mental, intellectual and social abilities of an individual affected by stroke.¹ Stroke rehabilitation enables the stroke survivor to perform his/her daily activities at an optimal functional level and helps the stroke survivor to participate in his/her social roles as independently as possible.² The stroke survivor relearns the skills that are lost or impaired due to brain damage following stroke through rehabilitation.³

An insult to the human brain due to stroke might have various effects on the stroke survivor, and hence healthcare professionals from various disciplines have to provide the stroke survivor with a patient-centred, comprehensive, multi-disciplinary rehabilitation.⁴ Unlike high-income countries (HICs), the resources for rehabilitation, especially the rehabilitation workforce and infrastructure, are very limited in many low and middle-income countries (LMICs).⁵ If we take India as an example, rehabilitation services are often unidisciplinary, driven predominantly by physiotherapists, with

lack of support from occupational therapists, speech therapists and so on. Many government-run district rehabilitation centres are non-functional and the private hospitals are staffed with only a physiotherapist in their rehabilitation centres.⁶ Given the scarce resources, the rehabilitation needs of the stroke survivors, especially in the LMICs, remain largely unmet.⁷ Provision of cost-effective, post-stroke multidisciplinary rehabilitation services for the stroke survivors therefore becomes crucial to address the unmet needs and growing magnitude of disability experienced by the stroke survivors in LMICs.

The past few years have seen a tremendous increase in the use of Smartphones by health professionals and also by the general public.⁸ Evidence from a recent systematic review suggests that Smartphones could be an extremely useful tool to educate patients to manage their health problems.⁹ Another systematic review on the use of Smartphone applications for stroke rehabilitation also demonstrates the advantages of Smartphone applications for provision of stroke-related information.¹⁰ These Smartphone applications are regarded as important by health professionals providing stroke rehabilitation themselves.¹⁰

In order to meet the growing need for post-stroke rehabilitation services in India, we developed a web-based Smartphone-enabled educational intervention for management of physical disabilities following stroke. This paper provides a detailed description of the intervention and the processes involved in its development. The paper also discusses the importance of such rehabilitation interventions for meeting the unmet needs of the stroke survivors.

DEVELOPMENT OF THE CONTENT FOR THE INTERVENTION

Systematic review of the available interventions

Evidence from systematic reviews in relation to stroke rehabilitation and information provision for stroke survivors and caregivers was extensively used to develop the intervention. We also conducted a comprehensive and a global systematic review on educational interventions for reducing disabilities in acquired brain injury to investigate the evidence that was available to develop this intervention.

Rehabilitation needs assessment study

The content of the intervention was developed primarily based on the needs expressed by the stroke survivors and caregivers who participated in a rehabilitation needs assessment study carried out exclusively to develop this intervention. The rehabilitation needs assessment study was carried out to guide the development of a need-based rehabilitation intervention and had two components in it. One was a structured survey with 50 stroke survivors and their caregivers to identify the various kinds of rehabilitation needs that they experience. The other was a detailed in-depth

interview with a subsample of the stroke survivors and caregivers selected for the survey. The purpose of the in-depth interviews was to gain a detailed understanding of the experiences of the stroke survivors in relation to accessing stroke rehabilitation services and their rehabilitation needs following a stroke. In-depth interviews with health professionals involved in the provision of stroke rehabilitation services were also carried out to understand the perspective of the health professionals about provision of stroke rehabilitation services, their knowledge about the existing Smartphone-based health interventions and their attitudes and opinions about the use of a Smartphone-enabled, care-supported education programme for domiciliary stroke rehabilitation.

Expert group for content development

In addition to the needs assessment, expert guidance was obtained from a team of eight highly qualified and experienced health professionals from various neurorehabilitation disciplines (physical medicine and rehabilitation, neuropsychiatry, clinical psychology, occupational therapy, physiotherapy, social sciences, information technology, public health and m-health) with both national and global expertise in the field of neuropsychiatric rehabilitation. The expert team also included three stroke survivors and their primary caregivers. All the team members were from Tamil Nadu and they were Tamil-speaking. The key characteristics of the expert group, such as their experience, expertise, global exposure and language, facilitated the development of a culturally specific, patient-centred intervention for management of physical disabilities following a stroke.

Framework of the intervention content

On the basis of the findings from the rehabilitation needs assessment study, guidance from the expert group, and available evidence from systematic reviews, the framework of the intervention content was designed. The content framework included five important sections related to post-stroke rehabilitation. The sections were:

1. Information about stroke (know more about stroke)
2. Exercises (home-based exercises)
3. Functional skills training (preparing oneself for daily living)
4. Activities of daily living (engaging in activities of daily living)
5. Assistive devices (devices to assist daily living).

CONTENT OF THE INTERVENTION SECTIONS

Know more about stroke

As the section title suggests, this section enables the stroke survivors and caregivers to know more about stroke, the impact of stroke on an individual experiencing it and advice from experts on the way forward (life after a stroke). The important subsections/topics

Table 1 Content of 'know more about stroke' section

Content of the intervention		
Main sections	Subsections	Videos
Information about stroke	<ul style="list-style-type: none"> ▶ What is a stroke? ▶ What is a transient ischaemic attack (TIA)? ▶ How does a stroke happen? ▶ Warning signs of a stroke ▶ What are the common symptoms of a stroke? ▶ How does a stroke affect your body? ▶ Risk factors for a stroke ▶ Common effects of a stroke ▶ Recovering from a stroke 	<ul style="list-style-type: none"> ▶ What is a stroke? ▶ How does a stroke happen? ▶ What is a transient ischaemic attack ▶ Symptoms of a stroke ▶ Effects of a stroke ▶ Modifiable and non-modifiable risk factors for a stroke ▶ Effects of a stroke on <ul style="list-style-type: none"> – Balance – Bowel and Bladder – Thinking – Pain – Physical problems – Sleep and fatigue – Sensation – Sleep and fatigue – Speech and language – Swallowing ▶ Recovery from a stroke by <ul style="list-style-type: none"> – Public health experts – a neuropsychiatrist – a neurologist – a physiotherapist – an occupational therapist – a clinical psychologist – a disability rights expert

and videos that this section includes are provided in [table 1](#).

The primary objective of having this section is to create awareness and enable the stroke survivors and their caregivers to gain more knowledge about stroke, because this would assist them in preventing recurrent stroke, modifying their lifestyle, making treatment decisions and planning for life after a stroke.

Home-based exercises

This section includes home-based, task-oriented exercises that the stroke survivors can practise in their home in order to maintain or improve their body fitness for functional activities. These exercises are based on eclectic treatment approaches to stroke rehabilitation (motor relearning, functional, neurodevelopmental frame of references for therapy) that enable the stroke survivors to use their affected parts of the body and engage in functional activities.

These home-based exercises include the use of equipment like a chair or bed and table that are commonly available in most homes in India. They do not require the purchase of any sophisticated exercise equipment. Principles of safety and risk/hazard prevention have been thoroughly considered while

developing this section. Some of the important sub-sections/topics and videos that this section comprises are listed in [table 2](#).

The objective of developing this section content is to enable the stroke survivors to understand the relevance of the conscious use of the affected parts of the body following a stroke and also the importance of exercises for engaging in functional activities rather

Table 2 Content of 'Exercises' section

Content of the intervention		
Main sections	Subsections	Videos
Exercises	<ul style="list-style-type: none"> ▶ Upper limb exercises ▶ Lower limb exercises ▶ Balance exercises ▶ Active exercises ▶ Exercises to improve upper limb function 	<ul style="list-style-type: none"> ▶ Passive upper limb exercises ▶ Passive lower limb exercises ▶ Active-assisted exercises for the lower limb ▶ Active exercises for the upper limb ▶ Exercises for the trunk ▶ Exercises for balance ▶ Improving awareness and function of the affected hand

than just exercising and improving the flexibility, strength and movement of the affected body part.

Preparing oneself for everyday living

Functional skills are a prerequisite to participate in everyday living. One should know how to get up from a lying down position. In order to sit properly and feed or groom, one should know how to transfer from a bed to a chair or a commode for bathing or toileting. These are very important to the stroke survivor who cannot or finds it difficult to move the affected part of his/her body. This section highlights functionally oriented tasks that the stroke survivors can learn in order to participate in their day-to-day activities.

Exercise training provided by a physiotherapist to the stroke survivors is directly related to the development of functional skills of the individual affected by stroke. Hence, this section stresses the importance of functional skills to participate in everyday living and preparing oneself for everyday living by acquiring functional skills. Some of the important subsections/topics and videos of this section are depicted in [table 3](#).

Engaging in activities of daily living

This section comprises adaptive methods and techniques to engage in activities of daily living like grooming, bathing, dressing and eating. The stroke survivors

Table 3 Content of 'Exercises' section

Content of the intervention		
Main sections	Subsections	Videos
Functional skills training	► Positioning the stroke survivor in bed and in a chair	► Positioning on – the Chair – – the Bed –affected side
	► Bed mobility	– the Bed – unaffected side
	► Transfers	– the Bed—Lying on the back
	► Standing up from a sitting	► Bed Mobility
	► Mobility/ambulation training	– Rolling on the bed
		– Scooting on the bed
		– Coming up to a sitting
		► Sit to Stand (moderate support)
		Transfers
		– Independent transfers (bed to chair/wheelchair)
		– Transfers with maximum support
		► Walking

Table 4 Content of 'Activities of daily living' section

Content of the intervention		
Main sections	Subsections	Videos
Activities of daily living	► Brushing	► Brushing
	► Feeding	► Feeding
	► Bathing	► Bathing
	► Grooming	► Grooming
	► Dressing	► Washing face
		► Wearing a T-shirt
		► Wearing a Shirt
		► Wearing a dhoti/lungi
		► Wearing a pant
		► Wearing a saree
		► Wearing a blouse
		► Undressing

can watch, learn and practise these adaptive techniques to independently perform their activities of everyday living. The content of this section is depicted in [table 4](#).

This section is very important from the viewpoint of both the stroke survivors and their caregivers. This is because learning to purposefully engage in one's own everyday living seems to be an important need and crucial task for the stroke survivors to independently participate in his/her personal, family and societal roles. Although the stroke survivors learn to do exercises and acquire knowledge to manage their problems post-stroke, the overall objective behind the acquisition of these skills and knowledge is to live a functionally independent life and perform their various roles at home and society actively ([table 5](#)).

Devices to assist daily living

This is a unique section that enables the stroke survivors and their caregivers to understand the importance of using assistive devices that are readily available in India and that can assist the stroke survivor to engage in their day-to-day activities independently and also with confidence. This section also includes devices that are tailor-made to the needs of the stroke survivors living in the southern part of India like an adapted saree, Velcro-based blouse, adapted dhoti and lungi, etc. This section also has devices that are not available in India but can be designed and fabricated

Table 5 Content of 'Devices to assist daily living' section

Content of the intervention		
Main sections	Subsections	Videos
Assistive devices	► Personal care aids	► Personal care aids
	► Mobility aids	► Mobility aids
	► Orthoses and supports	► Orthoses and supports

by the stroke survivors themselves and their caregivers, for example, the universal cuff that can assist the stroke survivor to use their affected hand for feeding, brushing, writing and grooming. The key topics covered under this section is provided in [table 5](#).

The primary objective of this section is to inform the stroke survivors of the importance of assistive devices that can be used to perform everyday activities independently and safely. Assistive devices can boost the confidence of the stroke survivor to engage in their everyday tasks. It also reduces the assistance and support provided by the caregivers, thereby reducing the physical strain in providing care and support for the stroke survivor in their daily living tasks.

DESCRIPTION OF THE INTERVENTION

Naming the application

This application was intended to educate the stroke survivors and their caregivers to manage their physical disabilities following stroke. Therefore, the web-based application was named ‘Care for Stroke’ to emphasise the importance of enhancing the life of individuals experiencing stroke and continuum of care that is essential for a stroke survivor.

Logo and tagline of the application

The logo of the application was created by the principal investigator himself under the supervision of experts from the field of disability, rehabilitation and design ([figure 1](#)). The logo depicts a stroke survivor accepting support from another person in a home environment and trying to mobilise himself/herself. The design of the logo stresses the importance of the stroke survivor accepting support from another person and actively engaging in functional activities while staying at home.

The tagline of the application is ‘Think Smart—Take Control’. This tagline emphasises the importance of proactive, innovative and smart planning for therapy and rehabilitation services that the stroke survivor and their caregivers should execute, outside the hospital environment. It also encourages the stroke survivors to take control of their problems following stroke and work towards an independent life after a stroke.



Figure 1 Logo of the application.

Design of the web-based application

This intervention is designed as a web-based application that uses a website as an interface (the front end). The introductory web page of the application is shown in [figure 2](#). Users can access the application not just from Smartphones but also from a computer, PDA, Tablet and even digital television that is connected to the internet using any standard web browser. Some of the key design features of this application are: User interface, content format, language.

User interface

An interface enables a user to interact with a system (Smartphone in this instance) to perform a task. For example: Navigating to different web pages in this website enables a user to find the video content that he/she prefers to watch. The users can watch the videos by navigating through user-friendly interfaces such as the touch and slide option which requires the users to either touch or slide the icons (ie, pictures and symbols) and pages in the application to watch the videos they want.

Content format

This application is exclusively designed to support digitised audio–visual content. More than 75% of the content of this application is in the form of videos. The users can interact with the images related to the main sections and watch the videos about stroke and the management of physical disability post-stroke



Figure 2 Introductory page of the ‘care for stroke’ application.

through this application. There is very minimal requirement for the users to read written information in this application.

Language

This application is built with multilingual functionality and it currently supports English and Tamil, the native language of the State of Tamil Nadu in India where it was piloted.

Technical description of the application

The application is built using a LAMP (Linux, Apache, MySQL, PHP) environment. The user interface of the application was designed using HTML5, CSS3, Bootstrap, Java Script, JQuery, Ajax, Google font API and Touch Swipe. It is to ensure that the user interface acts as a responsive and interactive design. Designing the application with these technologies supports the application to be installed and run on multiple devices like desktop, laptop, iPhone, iPad, Android devices and Windows devices.

The back end of the application was built in PHP5 (PHP—Hypertext Processor) language. This is to facilitate the user to interact with the database (MySQL) and view the requested information without any difficulty. Given the issues with video streaming in a country like India (ie, very slow internet connectivity and streaming), this application uses Cloud Flare CDN (Content Delivery Network) that enhances the quality and speed of the video streaming while the user is accessing the videos from the application.

This application also has an administrator module, where the administrator can monitor all the activities of the users who have logged into the application. It can also generate different types of reports of the user interaction with the application. Some of the key information that could be monitored are:

- ▶ The title of the sections and videos viewed,
- ▶ Duration of the logged in session
- ▶ Date and time of viewing
- ▶ Number of sections and videos watched during a logged in session.
- ▶ Device used for logging in
- ▶ Time spent on application,
- ▶ Geo-location information.

STRUCTURE AND FUNCTIONALITY OF THE APPLICATION

Registered website

This web-based application can be accessed from the registered website name <http://www.careforstroke.com>

Home page

The application has a home page that briefly describes stroke and stroke-related disability in the vernacular (Tamil). First-time users cannot access the intervention without registering themselves. This is to ensure proactive engagement of the users, observe their

utilisation pattern and to generate utilisation reports for future evaluations. The home page provides details of registration with an icon to register the first-time users. Users who have already registered to access the intervention can use the same icon to access the sign-in page ([figure 2](#)). There is a drop-down icon in the home page to change the language of the application if required. Currently, the application pages have the descriptions in English and Tamil.

Sign-in page and registration

This page contains an icon for first-time users to register and the sign in boxes with user name and password sections to be filled by the user to sign into the application.

Registration page

This page contains a drop-down box, where the user can identify and register themselves as a stroke survivor or caregiver of the stroke survivor. This helps the investigator or administrator to monitor the engagement and usage of the application by the stroke survivors and caregivers separately. On the basis of the options chosen, the user will be redirected to the specific registration page with drop-down options and text boxes to fill in the user details requested and register onto the application. After completing the registration, users will be redirected back to the sign-in page. Registration requires the users to have a username and password to ensure identity and privacy ([figure 3](#)).

Intervention page

After the user signs into the application successfully, the application is redirected to the main intervention page. This page contains brief written information about the intervention and five important sections that contain the content of the 'care for stroke' intervention ([figure 4](#)).

Sections: There are five main sections displayed as photographic icons on the intervention page which can be touched and explored further ([figure 4](#)). These five sections contain digitised information (videos) about stroke and the various aspects that a stroke survivor can view and understand about the management of the physical disabilities following a stroke ([figure 5](#)).

Subsections: When the user touches an icon on the section page, it is redirected to the corresponding subsection page that comprises topics (subsections) that the respective section contains. For example, the main intervention page will contain a photograph of the stroke survivor performing his Activities of Daily Living—ADL (intervention page); if the user touches this icon, it will take him or her to the ADL section ([figure 5](#)). If the user touches this ADL section icon, the web page will be redirected to the ADL subsection page that contains topics with video icons (images) related to ADL, in this instance, stroke survivors



Figure 3 Registration page.

performing brushing, feeding, dressing, etc. Please find the section web page in [figure 6](#).

Content digitised videos: When the user touches a topic in the subsection, the web page will be redirected to a page that contains detailed information about that topic in the form of 3–5 min video clips. For example, if the user touches the topic ‘Wearing a blouse’, the web page will be redirected to a video clip related to that topic. These videos are streamed online through internet or mobile internet networks and can be watched by touching the play button on the video clip. Please find the video section of the application in [figure 7](#) below.

Shuffling between the web pages

Users can shuffle between the pages by either

1. Pressing the back button on the Smartphone
2. Pressing the back icon on the web page
3. Sliding the web pages back and forth using the touch screen option on the Smartphone.

In addition to this, the user can return to the main intervention page at any time by touching the logo which is located on top of every web page of the application.

Administrator module

This Smartphone-enabled intervention is built with an administrator module, where the usage and utilisation



Figure 4 Intervention page.

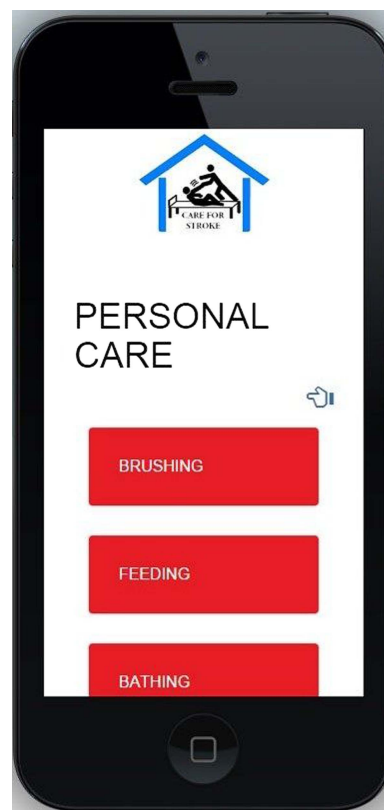


Figure 5 Section page.



Figure 6 Subsection page.

patterns of this application by the users can be tracked continuously and reports can be generated to inform the feasibility of this intervention and also to monitor the progress of any programmes/research projects related to this intervention when scaled up to a larger community of stroke survivors. The administrator can also add videos onto (or remove videos from) the application as and when required, thereby customising or improvising the content of the intervention according to the needs of the users. The module is protected and strictly secured through a username and password to ensure privacy and confidentiality of the user information.

DISCUSSION

Stroke is one of the leading causes of death and disability worldwide.¹¹ Globally, nearly six million people die from stroke each year, and much of this

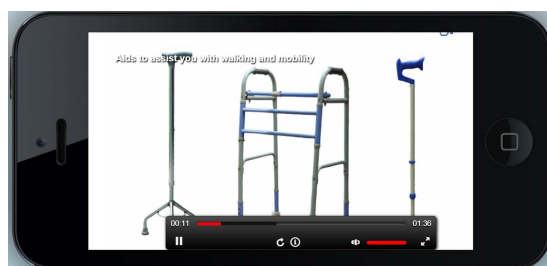


Figure 7 Video section of the application.

stroke burden is borne by LMICs.¹² Though the primary focus of many LMICs, including India, is to prevent stroke by reducing the prevalence of its risk factors, similar attention should also be given to those who survive a stroke and are disabled post-stroke.^{13 14}

Unlike HICs, organised multidisciplinary rehabilitation services for stroke survivors are not available in many LMICs.^{15–17} Given the context of many LMICs with a scarce rehabilitation workforce and resources for rehabilitation, it is critically important to develop innovative post-stroke rehabilitation interventions that could address the growing magnitude of post-stroke disability and meet the rising need for rehabilitation services in these countries.

The international telecommunication union estimated that six billion people were mobile phone users during 2011 globally, which is equivalent to 87% of the world's population. This report has also documented that India is one of the top markets for Smartphone sales globally.¹⁸ The management of chronic diseases using Smartphone technology has been described in a recent systematic review.¹⁹ This review identified 15 Smartphone applications for management of chronic conditions. Out of these 15 applications, there was only one application called Mayo clinic meditation that was similar to the 'Careforstroke' application. The Mayo clinic application helped patients practise meditation through a 15 min training video on meditation.

Some of the Smartphone applications used in stroke rehabilitation in HICs include the Dr Droid application that helps therapists to administer and track upper limb exercises for stroke rehabilitation,²⁰ the Think-FAST application that features stroke prevention information and a list of stroke unit locations in Australia²¹ and PTX, a physiotherapy exercise application for individuals with any kind of neurological conditions that includes a pictorial description of the exercises for stroke survivors.²² The National Institute of Clinical Excellence (NICE) guidelines for long-term stroke rehabilitation also recommend the use of Smartphones for communication problems in patients with stroke.²³

A chronic condition like stroke requires uninterrupted therapeutic care and constant monitoring during the entire continuum of recovery.²⁴ In the absence of any organised stroke care services and with the limited resources for rehabilitation, a Smartphone-enabled educational intervention for management of disabilities could be a strategy to meet the substantial rehabilitation needs of stroke survivors in India. The evidence concerning the use of Smartphones in chronic disease care in India is just emerging and the use of Smartphones in health interventions to combat diseases like diabetes, hypertension and cardiovascular diseases is progressively being investigated.²⁵ Adoption of this strategy could possibly reduce the barriers to access and availability of stroke

rehabilitation services. It could also aid in efficient and sustained monitoring of patient progress throughout the continuum of care.

'Care for stroke' is a Smartphone-enabled educational intervention for management of physical disabilities following a stroke. The content of the intervention was developed systematically and primarily based on the needs of the stroke survivors and informed by existing global evidence. It includes inputs from highly qualified and experienced multidisciplinary stroke rehabilitation professionals in a digitised audio-visual format that is more entertaining to watch and learn compared to the other methods of patient education such as an educational workbook and group teaching or lectures.

This intervention is culture-specific and language-specific, and therefore the users can easily understand and adapt the techniques to manage their post-stroke-related disabilities. Since the intervention is loaded onto a Smartphone, the user can access the intervention as and when they need. Unlike television and DVD players, Smartphones are portable and handheld and hence it might aid the user to access the intervention conveniently (without having to plug wires, operate a remote to watch videos or depend on electricity).

This Smartphone-based, technology-driven intervention can be less demanding in terms of the physical abilities required by the users to learn, when compared with other kinds of educational interventions like attending group sessions, using a stroke workbook or watching a DVD educational material about stroke. The application for accessing the intervention is web-based, and hence the users can also access the content through their laptops, desktops and tablets if required.

From the point of view of programme managers and evaluators, this kind of web-based educational intervention can continuously monitor the usage and utilisation pattern of the intervention by each user, and it can be helpful to generate reports to monitor the efficiency and effectiveness of this intervention while scaling up, without having to contact the users. Since the intervention is Smartphone-enabled and web-based, the user can contact the service provider directly by dialling the contact numbers on the Smartphone or by making a skype call using the mobile internet services.

This Smartphone-enabled intervention might also motivate the caregivers and family members to comprehend the importance of stroke rehabilitation and support the stroke survivors in utilising the key aspects of the intervention in their everyday life. From a financial perspective, the cost of using this Smartphone-enabled intervention might be less costly compared to the other ways of accessing information about stroke and the ways to manage post-stroke physical disability from rehabilitation experts or hospitals.

The 'Care for stroke' application is currently under pilot testing for its feasibility and acceptability with a small group of stroke survivors and their caregivers

in Chennai, India. If this application is found feasible and acceptable, the investigators intend to look at the clinical and cost-effectiveness of this intervention. To date and to the best of our knowledge, there has not been a web-based, Smartphone-enabled educational application and intervention for stroke survivors with a primary focus on the rehabilitation aspect of the stroke. In a global context and from a public health perspective, 'Care for stroke' is one such kind of innovative intervention which could be tested not just for its feasibility and acceptability but also for its clinical and cost-effectiveness through rigorously designed, randomised clinical trials. It is very important to test this intervention in LMICs where the rehabilitation and information needs of the stroke survivors seem to be substantial and largely unmet.

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Contributors SK (Doctoral student at LSHTM) conceived the study, designed and developed the intervention and drafted the manuscript. GVSM and HK played a pivotal role in conceptualising the stages involved in the development of the intervention and reviewed the manuscript. SM provided substantial guidance for the technical development of the web-based application. SG provided guidance in the concept of the research study.

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Chapter 6

Evaluation of the Feasibility and Acceptability of the ‘Care for Stroke’ Intervention in India: a Smartphone-enabled, Carer-supported, Educational Intervention for Management of Disability Following Stroke.

Preamble

The newly developed ‘Care for Stroke’ intervention was initially field-tested with a group of stroke survivors and their carers in order to identify the operational difficulties in using the intervention. Based on the findings from the field-testing, the intervention was revised and finalised with the approval from expert committee that was organized to guide the development of the intervention. The refined, finalised version of the intervention was pilot-tested for its feasibility and acceptability among the stroke survivors and their carers in an Indian context.

This research paper is a combined presentation of the field-testing and pilot-testing of the ‘Care for Stroke’ intervention. The manuscript of this study was submitted to the BMJ Open and it was published recently. The published version of this research paper is included as a chapter.

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Principal Supervisor	PROF GVS MURTHY
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<p>For multi-authored work, give full details of your role in the research included in the paper and in the preparation of the paper. (Attach a further sheet if necessary)</p>	<p>I conceived the study, designed the study, collected the data and analysed the study data under the guidance of my supervisors Prof GVS Murthy and Dr Hannah Kuper. I also wrote the first draft of the manuscript and prepared subsequent revisions with consideration of comments from my supervisors and other co-authors.</p>
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Date: 7/8/2015

Supervisor Signature: 

Date: 7/8/2015

BMJ Open Evaluation of the feasibility and acceptability of the 'Care for Stroke' intervention in India, a smartphone-enabled, carer-supported, educational intervention for management of disability following stroke

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ABSTRACT

Objectives: (1) To identify operational issues encountered by study participants in using the 'Care for Stroke' intervention; (2) to evaluate the feasibility and acceptability of the intervention.

Design: Mixed-methods research design.

Setting: Participant's home. Participants were selected from a tertiary hospital in Chennai, South India.

Participants: Sixty stroke survivors treated and discharged from the hospital, and their caregivers.

Intervention: 'Care for Stroke' is a smartphone-enabled, educational intervention for management of physical disabilities following stroke. It is delivered through a web-based, smartphone-enabled application. It includes inputs from stroke rehabilitation experts in a digitised format.

Methods: Evaluation of the intervention was completed in two phases. In the first phase, the preliminary intervention was field-tested with 30 stroke survivors for 2 weeks. In the second phase, the finalised intervention was provided to a further 30 stroke survivors to be used in their homes with support from their carers for 4 weeks.

Primary and secondary outcome measures:

Primary outcomes: (1) operational difficulties in using the intervention; (2) feasibility and acceptability of the intervention in an Indian setting. Disability and dependency were assessed as secondary outcomes.

Results: Field-testing identified operational difficulties related to connectivity, video-streaming, picture clarity, quality of videos, and functionality of the application. The intervention was reviewed, revised and finalised before pilot-testing. Findings from the pilot-testing showed that the 'Care for Stroke' intervention was feasible and acceptable. Over 90% (n=27) of the study participants felt that the intervention was relevant, comprehensible and useful. Over 96% (n=29) of the stroke survivors and all the caregivers (100%, n=30) rated the intervention as excellent and very useful. These findings were supported by qualitative interviews.

Conclusions: Evaluation indicated that the 'Care for

Strengths and limitations of this study

- A phased approach to the development and evaluation of the intervention helped refine the intervention.
- Mixed research methods were used for evaluation of the intervention.
- Recruitment of participants from only one centre.
- Stringent inclusion criteria for participant recruitment.

Stroke' intervention was feasible and acceptable in an Indian context. An assessment of effectiveness is now warranted.

BACKGROUND

Each year, about 15 million people suffer stroke globally. One-third of stroke survivors experience permanent disability.¹ Increased population aging and the rising prevalence of risk factors for stroke will further increase the number of people living with stroke-related disabilities.² Projections by the WHO show that the disability-adjusted life years lost to stroke will rise from 38 million in 1990 to 61 million by 2020.¹ These projections imply an overwhelming global demand for stroke rehabilitation services.³ This is especially true in low- and middle-income countries (LMICs), which bear a substantial amount of the global burden of stroke⁴ yet have few rehabilitation services available.

The high burden of stroke but lack of rehabilitation services creates the need to develop and evaluate innovative strategies such as the use of mobile phones or smartphone-based applications for provision of healthcare services.⁵ These mobile health

(Mhealth) strategies capitalise on the core functionalities of a mobile or smartphone and are strongly recommended by the WHO for bridging the gaps in accessibility to health services globally.⁶ This was the rationale for developing 'Care for Stroke', which is a web-based, smartphone-enabled, caregiver-supported, educational intervention for management of physical disabilities following stroke. This Mhealth intervention draws on the principles of both medical sciences and information technology to address the gaps in access to stroke rehabilitation services for stroke survivors in a systematic way, as recommended by the Medical Research Council.^{7 8} The intervention has been developed with a specific focus on LMICs, where the resources available for rehabilitation are often very limited. To our knowledge, there are no stroke rehabilitation interventions enabled through Mhealth platforms that are available and relevant to LMICs, such as India, where the resources for rehabilitation are limited and the unmet needs of stroke survivors are substantial.⁹ Therefore, it was decided to evaluate this newly developed rehabilitation intervention in an Indian context.

The research study protocol which describes the participatory development of the intervention is available elsewhere.¹⁰ The present paper describes the field-testing and pilot-testing of the intervention. The purpose of field-testing was to provide the newly developed intervention to stroke survivors and their caregivers and assess any initial operational difficulties experienced. This enabled revision and refinement of the intervention before it was tested for feasibility and acceptability (pilot-testing).

PRIMARY OBJECTIVES OF THE EVALUATION

1. To identify operational issues encountered by the study participants through field-testing
2. To revise the intervention based on the findings from the field-testing
3. To evaluate the feasibility and acceptability of the intervention among the stroke survivors and their caregivers through pilot-testing.

METHODS

Mixed-methods research design

This study applied mixed research methods in order to collect more comprehensive evidence regarding the research question. The mixed-methods approach was specifically chosen because it is known to encourage the use of multiple worldviews and is a pragmatic approach to research pertaining to development of complex interventions.¹¹

Participant selection and recruitment

Only one hospital (TS Srinivasan Institute of Neurological Sciences, Voluntary Health Services (VHS) Multispecialty Hospital, Chennai) provided permission to recruit participants. The newly developed 'Care for Stroke' intervention was evaluated with a sample of 60

adult stroke survivors and their caregivers living in Chennai, South India (30 pairs of stroke survivors and their caregivers for field-testing and 30 pairs for pilot-testing). All were previously treated for their stroke at the VHS Hospital, which has an admission rate of three to four stroke patients per week. Given the hospital admission rate and the time that was available within the PhD project, we were able to recruit only 30 pairs of participants for field-testing and 30 pairs for pilot-testing.

Study participants were purposively selected from the hospital records and invited to the hospital for follow-up. Contact details of participants were retrieved from their hospital records. During the follow-up consultation, the stroke survivor was assessed for their eligibility to participate in the study by a neurologist. If the participant was determined to be eligible, they were provided with a detailed background of the study and its purpose by the investigator (KS). Informed written consent was obtained from those who agreed to participate in the study.

Inclusion criteria

- Adults (aged ≥ 18 years)
- Recent diagnosis of first-ever stroke as defined by the WHO¹² within 3–6 weeks of the recruitment
- Severity of stroke: minor and moderate (score 1–15, according to the NIH Stroke Scale^{13 14}).
- Stroke survivor medically stable (reaching a point in medical treatment where life-threatening problems following stroke have been brought under control)
- Post-stroke functional status of the stroke survivor: requiring assistance of at least one person to perform daily activities such as transfers, self-care and mobility (scoring less than the maximum score obtainable in one or more components of the Barthel Index (BI)¹⁵)
- Stroke survivor residing with a primary caregiver (family member) at home.

Exclusion criteria

- NIH Stroke Scale score >15
- Severe cognitive difficulties (scoring >1 in Orientation, Executive function, Inattention and Language components of the NIH Stroke Scale for cognition)¹⁶
- Severe communication problem (scoring >1 in Dysarthria and Best Language component of the NIH Stroke Scale^{13 14})
- Severe comorbidities (severe psychiatric illness, hearing loss, vision loss)
- Stroke survivor functionally dependent because of other pre-existing conditions (eg, amputation, fracture, dementia)
- Stroke survivor without a primary caregiver
- Stroke survivor unwilling/unable to adhere to the study protocol
- Did not meet the training requirements regarding operation of a smartphone

About the intervention

The 'Care for Stroke' intervention was delivered through a smartphone and included information about stroke and the ways to manage post-stroke disabilities. This was provided through text and videos in the local Tamil language. The intervention is web-based and hence requires an internet connection. It includes modules on information about stroke, home-based exercises, functional skills training, activities of daily living, and assistive devices. Further details about the intervention have been described previously¹⁷ and as an online supplementary file 1.

Training and administration of the intervention

The educational intervention was preloaded on to the smartphone. The stroke survivor and their caregiver received 20–30 min of training from the investigator (KS) on access and use of the intervention via the smartphone. Participants were then provided with a smartphone preloaded with the 'Care for Stroke' intervention (ie, a smartphone along with the intervention loaded on to it) and asked to try it out on their own. Three or more errorless attempts to retrieve the required part of the intervention from the smartphone were considered successful training.

Participants were asked to use this intervention at home for 2 weeks during the field-testing phase and for 4 weeks during the pilot-testing phase. The caregivers of stroke survivors selected for this study were asked to support the stroke survivors in accessing the intervention from the smartphone as and when required.

Direct observation and interviews during field-testing

Utilisation of the smartphone-enabled intervention and the support provided by the caregivers to the stroke survivors was assessed by the investigator (KS). Direct participant observation (with observation checklist) and short unstructured interviews related to the objectives of the field-testing were carried out at each participant's home during this phase. Key issues assessed included:

- A. Relevance and comprehensibility
- B. Operational difficulties and user-friendliness
- C. Technical issues
- D. Training needs

Assessment of feasibility and acceptability during pilot-testing

Feasibility and acceptability of the intervention was assessed primarily through a semistructured questionnaire administered to stroke survivors and primary caregivers. The majority of questions in the questionnaire were related to satisfaction and patient experience. The questionnaire predominantly included closed-ended questions with ordered (Likert scale) responses (see online supplementary file 2). The frequency of each response was calculated separately for each question in the questionnaire. The questionnaire schedule was developed, translated and pilot-tested before it was administered. In addition to this, participants were also asked specific open-ended questions related to the objectives of the pilot-testing.

Participants' responses to the questions were transcribed verbatim and translated into English. Transcribed data were then analysed using the framework approach.¹⁸

Assessment of clinical outcomes

Independence in activities of daily living was assessed using the BI,¹⁵ and disability was assessed using the Modified Rankin Scale (MRS).¹⁹ The investigator (KS) carried out this assessment to investigate the feasibility of using these clinical outcome measures in a future larger trial of the intervention.

Analysis of clinical outcome measures

Pre-intervention and post-intervention scores for the BI and MRS were analysed using the paired Student *t* test method.

RESULTS OF THE FIELD-TESTING

The demographic and clinical characteristics of the stroke survivors and their caregivers are described in table 1.

Ability of participants to access the intervention from a smartphone

Stroke survivors

Among 30 stroke survivors selected for the field-testing, 37% (11 participants) had used a smartphone before their stroke. During the field-testing, seven stroke survivors (23%; six men and one woman) independently accessed the intervention through a smartphone. All remaining participants were helped by their caregivers to access the intervention—especially in operating the smartphone to access desired videos. Three stroke survivors (10%) used headphones to listen to the audio while watching the videos. Stroke survivors preferred to use their affected hand to hold or stabilise the smartphone and operate it using their unaffected hand. Most often, stroke survivors preferred to watch the video first, understand it and then practise the techniques shown at a later point.

Caregivers

Among the caregivers included in field-testing, 93% (n=28) were smartphone users before the intervention and 70% (n=21) owned a smartphone. None of the caregivers had difficulty in operating the smartphone and accessing the intervention. They generally helped the stroke survivors to access the intervention and directed them to watch inter-related videos.

Technical/operational issues encountered by the participants during field-testing

Operational issues encountered by participants included:

1. Poor connectivity inside the home
2. Video-streaming delay because of low 3G data allowance
3. Low audio levels (eg, participant resided in a noisy area)

4. English version of the intervention not understandable, and Tamil version needed
5. Inability to access various web pages of the intervention by sliding the touchscreen on the smartphones
6. Inadequate clarity of the pictures.

In addition, five stroke survivors (17%) and 15 caregivers (50%) expressed that they required more indepth training and an operational manual to adequately learn and access the intervention from the smartphone.

Revision and finalisation of the intervention

The findings from the field-testing were shared with an expert group consisting of professionals from various rehabilitation disciplines experienced in stroke rehabilitation. After receiving their feedback and advice, the

preliminary field-tested version of the 'Care for Stroke' intervention was revised. All the operational issues identified during the field-testing (eg, the connectivity issues, poor audio/video quality, delayed video-streaming, language issues, touchscreen sliding functionality) were rectified by the technical consultants. This revised version of the intervention was once again shared with these expert group members for their review and approval for finalisation. The finalised version of the intervention was then used for pilot-testing.

RESULTS OF THE PILOT-TESTING

The demographic and clinical characteristics of the stroke survivors and their caregivers are described in [table 1](#).

Table 1 Demographic and clinical characteristics of the stroke survivors and caregivers in field-testing and pilot-testing

Characteristic	Participants in field-testing	Participants in pilot-testing	Statistical difference between the groups (p value)
Stroke survivors			
Gender			
Male	20 (67%)	18 (60%)	0.59
Female	10 (33%)	12 (40%)	0.59
Age (years)	54.2 (14.7)	57.9 (11.2)	0.27
Education, primary school or higher	24 (80%)	26 (87%)	0.49
Currently married	27 (90%)	30 (100%)	0.08
Working before stroke	26 (87%)	16 (53%)	0.0048*
Currently working	15 (50%)	3 (10%)	0.0007*
Stroke type			
Ischaemic	27 (90%)	24 (80%)	0.28
Haemorrhagic	3 (10%)	6 (20%)	0.28
Stroke severity			
Minor	12 (40%)	8 (27%)	0.27
Moderate	18 (60%)	22 (73%)	0.27
Affected side			
Right	18 (60%)	18 (60%)	1.00
Left	12 (40%)	11 (37%)	0.79
Both	0 (0%)	1 (3%)	0.31
Level of dependence			
Independent-personal care	15 (50%)	7 (23%)	0.032*
One-person assistance	15 (50%)	23 (77%)	0.032*
Receiving physiotherapy	8 (27%)	8 (27%)	1.00
Using mobility aids	9 (30%)	6 (20%)	0.37
Smartphone user	11 (37%)	3 (10%)	0.015*
Caregivers			
Gender			
Male	15 (50%)	11 (37%)	0.30
Female	15 (50%)	19 (63%)	0.30
Age (years)	31.6 (7.66)	39.5 (13.7)	0.008*
Education, primary school or higher	30 (100%)	29 (97%)	0.31
Employed	21 (70%)	27 (90%)	0.05
Primary caregiver	16 (53%)	25 (83%)	0.012*
Owns a smartphone	21 (70%)	21 (70%)	1.00
Smartphone user	28 (93%)	18 (60%)	0.012*

Values are mean (SD) or N (%).

*Significant difference between groups, $p < 0.05$.

Feasibility for recruitment

Study recruitment took place from December 2014 to February 2015. We identified 46 stroke survivors from the hospital records, of whom 30 were recruited (cause of exclusion: death, 2; lack of contact details, 2; ineligible, 4; resided far from hospital, 4; refusal, 4).

Feasibility for training and utilisation

Nearly 80% (n=24) of the stroke survivors required support from their caregivers to use the intervention, 13% (n=4) said that they could manage by themselves, and 3% (n=1) required additional training to access the intervention. In contrast, 77% (n=23) of the caregivers managed the application themselves, 13% (n=4) required support from other caregivers at home and 7% (n=2) required further training. Details of the training needs and pattern of utilisation by study participants are provided in [table 2](#).

Smartphone utilisation among study participants

Ninety per cent (n=27) of the stroke survivors had a smartphone at home, and over 40% (n=12) of them had either mobile or broadband internet connection at their home before the intervention. Only 23% (n=7) of the stroke survivors owned a smartphone themselves. Nearly three-quarters (70%, n=21) of primary caregivers owned a smartphone, and about 60% (n=18) of these used all the features of their smartphone. One family member with thorough knowledge and experience of using a smartphone was available at a minimum for each stroke survivor to help them use the intervention.

Relevance of the intervention

All participants reported that the intervention videos related to 'the information about stroke, activities of daily living and exercises' were very relevant to their rehabilitation needs following stroke. Almost all (97%, n=29) of the stroke survivors felt that the intervention was most relevant to their current rehabilitation needs. Most of the carers (77%, n=23) reported that the intervention was definitely relevant to the needs of the stroke survivors.

Although 50% (n=15) of the stroke survivors included in the study were functionally independent, they still found the intervention relevant to them. All the participants found the 'information about stroke' section very relevant, especially in terms of gaining awareness about the warning signs of stroke, and knowledge about stroke, its impact and various aspects of recovery ([table 2](#)). The caregivers reported that they gained confidence and motivation to support the stroke survivor in their family after watching the videos.

Comprehensibility of the intervention

When the study participants were asked about the overall comprehensibility of the intervention, 63% (n=19) of stroke survivors and 77% (n=23) of carers felt that the intervention was easily comprehensible.

Participants attributed this to the people who acted in the videos and the language in which the audio descriptions were presented.

The stroke survivors and caregivers reported that they understood various sections of the intervention through the photographs in the application alone. None reported problems in either understanding the videos or the corresponding voiceovers. Participants stated that high-definition videos and simple language helped them comprehend the intervention at ease.

Stroke survivors reported enjoyment from learning about the 'Dos and Don'ts' after stroke and the ways to manage daily living. They explained that they understood the recovery process and the ways to prevent another stroke after watching the intervention videos.

One stroke survivor explained:

I was so depressed because of this problem. I did not know whether this could come back like heart attack. Watching the videos about risk factors was such a relief. Now I understood that, if I control my sugar and have a proper balanced diet, I can be away from another stroke

User-friendliness of the smartphone-enabled intervention

The intervention was loaded on to a Micromax Canvas A102 Doodle3 Smartphone. This smartphone had configurations appropriate for accessing the intervention with good connectivity, streaming speed and picture clarity, and was relatively cheap. Other key aspects of user-friendliness of the intervention included:

1. Light weight of the smartphone (584 g)
2. Wide screen of the smartphone (7 inches)
3. Video/picture quality and detailing (high definition)
4. Streaming speed (on demand—content delivery network (CDN))
5. Application design and access features (based on the needs expressed by the stroke survivors)

A stroke survivor reported:

It's good that this is in a video format—It would be very difficult for me to read or understand formal Tamil dialects with the problems in my eyes. I always like to watch TV and hence I quite like the idea of teaching us 'what to do' through videos. Compared to reading from a book, this is not so boring as well

Usefulness of the intervention videos

Fifty seven percent (n=17) of stroke survivors and 47% (n=14) of carers reported that the intervention was very useful to them. The overall rating that the participants provided for the usefulness of the intervention is presented in [table 2](#). Stroke survivors explained that the video format of the intervention was very motivating. They felt that the intervention provided very useful information about their problem, the causes of their stroke, and the ways to manage their recovery independently. A stroke survivor who was unable to transfer or walk without support said:

Table 2 Details of participant responses from the satisfaction survey (pilot-testing)

	Initial impression about the intervention					
Participants	Interesting	Encouraging	Motivating	Consoling	All	None
Stroke survivors	7 (23%)	3 (10%)	1 (3%)	17 (57%)	2 (7%)	0 (0%)
Caregivers	9 (30%)	6 (20%)	10 (33.3%)	4 (13.3%)	1 (3.3%)	0 (0%)
Need for training and support to access the intervention						
	Need support from others	Can manage myself	Need training	Need training and support from others	Not sure	
Stroke survivors	24 (80%)	4 (13%)	1 (3%)	0 (0%)	1 (3%)	
Caregivers	4 (13%)	23 (77%)	2 (7%)	0 (0%)	1 (3%)	
Overall confidence to use the intervention						
	Definitely confident	Confident to a greater extent	Confident to some extent	Confident to a small extent	Not confident	
Stroke survivors	3 (10%)	9 (30%)	17 (57%)	1 (3%)	0 (0%)	
Caregivers	17 (57%)	12 (40%)	1 (3%)	0 (0%)	0 (0%)	
Utilisation pattern of the intervention						
	More than once a week	Whenever possible	More than once a day	Whenever necessary	Did not use	
Stroke survivors	15 (50%)	14 (47%)	1 (3%)	0 (0%)	0 (0%)	
Caregivers	14 (47%)	9 (30%)	2 (6%)	5 (17%)	0 (0%)	
Practising the skills learnt from the intervention						
	Always	Frequently	Occasionally	Rarely	Never	
Stroke survivors	7 (23%)	16 (53%)	6 (20%)	1 (3%)	0 (0%)	
Caregivers	7 (23%)	15 (50%)	8 (27%)	0 (0%)	0 (0%)	
Overall usefulness of the intervention						
	Definitely useful	Useful to a greater extent	Useful to some extent	Useful to a small extent	Not useful	
Stroke survivors	19 (63%)	9 (30%)	2 (7%)	0 (0%)	0 (0%)	
Caregivers	9 (30%)	20 (67%)	1 (3%)	0 (0%)	0 (0%)	
Overall likeableness of the intervention						
	Yes definitely	Yes to a greater extent	Yes to some extent			
Stroke survivors	17 (57%)	12 (40%)	1 (3%)			
Caregivers	27 (90%)	3 (10%)	0 (0%)			
Overall rating for the smartphone-enabled intervention						
	Excellent	Very useful	Satisfactory			
Stroke survivors	16 (53%)	13 (43%)	1 (3%)			
Caregivers	20 (67%)	10 (33%)	0 (0%)			

Continued

Table 2 Continued

Participants	Initial impression about the intervention				
	Interesting	Encouraging	Motivating	Consoling	All
Overall rating for the usefulness of the intervention					
Stroke survivors Caregivers	Extremely useful	Very useful	Useful to an extent		
	11 (37%)	17 (57%)	2 (7%)		
	16 (53%)	14 (47%)	0 (0%)		
Interesting sections of the intervention for the participants					
Stroke survivors Caregivers	All sections	Stroke information section	Stroke information and exercises sections	Stroke information and ADL sections	Stroke information and functional skills sections
	12 (40%)	7 (23%)	5 (17%)	4 (13%)	1 (3%)
	17 (57%)	5 (17%)	4 (13%)	2 (7%)	2 (7%)
Values are N (%). ADL, activities of daily living.					

Values are N (%).
ADL, activities of daily living.

I can now move from my bed to chair with some support from my sister. I am very happy to have achieved this. I saw the videos on 'how to move from one place to another with support' and I practiced it with my sister. Thank you for helping me with your videos. I am planning to learn more from it

Almost all stroke survivors (96%, n=29) felt that the intervention videos were self-explanatory. The carers explained that the stroke survivors were able to accept the importance of engaging in their daily living tasks and becoming as independent as possible in their lives.

Acceptability of the intervention

Two key features of the intervention that were most strongly valued by the majority of study participants were:

1. The Tamil audio descriptions of the intervention (local language)
2. The content of the intervention, especially the exercises and daily living task sections, explained through demonstration by individuals who resembled stroke patients from Tamilnadu.

A stroke survivor explained:

I didn't know that something like this is available in Chennai, I thought all these were in foreign countries. My son showed me some videos where doctors are speaking in English and I could not understand much. But I was able to understand many things from these videos on the phone—it was in Tamil so it was very easy

Stroke survivors expressed that they were motivated and encouraged to see the actual performance of daily living tasks using one-handed techniques by someone like them in the videos.

A stroke survivor reported:

I am surprised that a person with stroke can do things by himself with the strong hand. It's eye opening. I felt, why can't I try. I am now trying some of the tasks that I saw from the videos, especially to use my hand to eat and dress myself.

Acceptability of the smartphone-enabled application

When the study participants were asked about the acceptability of the intervention, more than half of stroke survivors (57%, n=17) and almost all carers (90%, n=27) reported that the intervention was definitely acceptable. Overall, 40% (n=12) of the stroke survivors and 10% (n=3) of the carers felt that the intervention was acceptable to a greater extent (table 2).

Stroke survivors found the portability of the intervention very useful to them, as they were able to comfortably watch the intervention videos anywhere they wanted. Stroke survivors also said that portability was very helpful in allowing them to watch the intervention privately (at home or elsewhere) without disturbing

others and without feeling shy about the discreet content.

It's a big family—we are nine people in a single home and one TV for all of us. The TV room will be busy all the time with lots of family members. This was one important reason why I prefer the smartphone instead of a DVD. I take this to any room or even my workplace and watch, it's convenient to carry and comfortable to watch—no one knows what I am watching. Otherwise people will feel pity about my situation

Caregivers reported that the smartphone required very minimal physical effort in terms of carrying or operating it.

A caregiver explained:

To get up from your place, go near TV to switch on, find the remote, give connections etc. It requires lots of work. I have to walk, bend and lift. I can't do all this with my own problems—this arthritis. This smartphone that you gave is a nice choice. Nothing other than movement of fingers to touch the screen is required. My wife watched it even when she was in bed sometimes.

Caregivers also appreciated the size of the smartphone screen, which was big enough to watch the videos comfortably without straining their eyes. They expressed that they were able to access the intervention from their own smartphone.

Caregivers found the repeatability of the intervention through simple touch and slide options very comfortable, especially in helping stroke survivors to remember important information from the intervention and to reinforce the importance of recovery. Caregivers also appreciated the design of the application and the ability to share the intervention videos with others globally.

A caregiver said:

My daughter, who lives in Singapore, wanted to know what this phone thing is all about. So we shared the details with her and asked her to watch it. Next day she called us and enquired whether we are watching it or not and she calls every day to find out what we watched.

Overall rating for the intervention

Fifty three percent (n=16) of stroke survivors and 67% (n=20) of carers rated 'Care for Stroke' as excellent.

The remaining participants rated the intervention as very useful (table 2).

Suggestions by participants

A major concern voiced by several participants (n=6) was internet connectivity, since intervention videos were streamed online through the web-based application service. These six participants were living in remote locations (outskirts of the city) with very poor connectivity. Participants with a broadband internet connection did not report any concerns about connectivity and online streaming issues. Two participants (7%) felt that the intervention could have been provided for longer, while several others reported that the intervention should have been provided when they were first hospitalised for stroke. Five participants (n=17%) requested a follow-up home visit by a member of the hospital team to reassess their recovery following stroke. Seven participants (n=23%) suggested that this intervention should be provided to every stroke survivor in every hospital and also to the public to prevent further strokes and its recurrence.

CLINICAL OUTCOMES

Results from the analysis of clinical outcomes showed statistically significant improvement in the scores of BI and MRS between before and after the intervention period (table 3).

DISCUSSION

The evaluation revealed that there was a minimum of one smartphone user and one smartphone in every participant's family. This indicates the availability and degree of smartphone penetration in a city like Chennai, which makes it potentially feasible for the smartphone-enabled carer-supported 'Care for Stroke' intervention to be widely used for provision of rehabilitation services in the future. The intervention was also found to be highly relevant, easily comprehensible, useful, likeable and satisfying to a greater extent. This implies a high level of acceptability of the intervention among the study participants. Given the lack of availability and accessibility of this kind of informational or educational intervention in India, 'Care for Stroke' fulfilled an important need among its users.

Table 3 Details from the analysis of the outcome measures (pilot-testing)

Outcome	Pre-intervention (baseline)	Post-intervention (end point)	Mean difference with 95% CI	Test for overall change in scores
Barthel Index	57.8 (26.6)	70 (25.8)	−12.2 (−15.3 to −9.0)	−7.86 p<0.00001*
Modified Rankin Scale	3.2 (0.8)	2.7 (1.1)	0.5 (0.3 to 0.7)	5.75 p<0.00001*

Values are mean (SD).

*Significant difference, p<0.05.

More than half of the stroke survivors were confident only to some extent in using the intervention, while this proportion was much lower among the carers. This in turn could explain why 20% (n=6) of stroke survivors and 25% (n=8) of primary carers used the intervention only occasionally and why two stroke survivors reported that the intervention was useful only to some extent. This may point to the need for more training for the stroke survivors in the use of the intervention.

Although the results from assessment of clinical outcomes were statistically significant, the amount of clinical gains obtained by the stroke survivors during the intervention period was relatively small²⁰. Furthermore, since there was no control group, we could not attribute the improvement to the intervention. Given the clinical significance and the small sample size in the pilot-testing, the statistical results obtained from the outcome measures have to be carefully interpreted²¹. However, the objective of using these clinical outcome measures was to look at the feasibility of their use in future trials of the intervention where a control group would be used to help attribute cause of improvement in clinical outcomes. Despite a short intervention period (4 weeks), these clinical outcome measures were able to detect statistically significant differences, thus establishing their feasibility for use in future clinical trials and effectiveness evaluations of the 'Care for Stroke' intervention.

Field-testing of the intervention helped the investigators to address key operational uncertainties that could have affected feasibility and acceptability. It also provided an opportunity to review and revise the intervention before it was pilot-tested. Pilot-testing of the intervention before its effectiveness evaluation assisted investigators to understand the factors that could affect feasibility and acceptability of the intervention. It provided valuable information that could be used to plan and organise rigorous effectiveness evaluation of the intervention in the future. A phased approach to the development of the intervention facilitated provision of proper consideration to the practical aspects of evaluation, providing assurance that the intervention could be delivered as intended in the future.²²

Accommodating multiple centres from the same geographical location for recruitment of participants for future studies could hasten the process of participant recruitment and thereby the evaluation process. Future studies could broaden the criteria for participant inclusion to more easily achieve the desired sample size and also to stratify the effects of the intervention by different subgroups of stroke survivors.

CONCLUSION

Evaluation of the 'Care for Stroke' intervention establishes its feasibility in an Indian context and its acceptability among the study stroke survivors and their caregivers. This makes it possible for us to affirm that

provision of a smartphone-enabled, carer-supported educational intervention for management of post-stroke disabilities could be a potential strategy to meet the growing need for stroke rehabilitation services in settings where rehabilitation resources are very limited. Adoption and modification of the 'Care for Stroke' intervention, with due attention to the cultural aspects of the target population, could potentially help to bridge the gaps in access to stroke rehabilitation services not just in India but also in other low-resourced countries where the rehabilitation needs of stroke survivors are substantial.

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Contributors KS conceived, designed and drafted the manuscript. GVSM and HK played a crucial role in conception of the research study and provided substantial guidance in designing and conducting the evaluation. SG and SN provided advice related to conception and actual conduct of the evaluation. CN assisted in carrying out the quantitative analysis.

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Chapter 7

Discussion

Preamble

This is the discussion chapter for the entire research study. The chapter includes discussion on the main research findings from each phase of the doctoral research study, strengths and limitations of the ‘Care for Stroke intervention, methodological strengths and limitations of the research study and implications of the finding in global and Indian context. The Chapter concludes with implications for future research on the intervention.

Discussion

Several evidence-based interventions have been developed for post-stroke rehabilitation in High Income Countries. However, it is not easy or practical to directly adapt these interventions to Low and Middle-Income Countries like India¹. This is because of the existing health care ecosystem, barriers in accessing rehabilitation services, limited resources for rehabilitation and the substantial unmet needs for stroke rehabilitation². Therefore rehabilitation interventions that are sensitive to the needs, culture and context of stroke survivors in countries like India need to be developed.

This research study aimed to develop and evaluate a smartphone-enabled, carer-supported educational programme for stroke survivors in India. To this end, I developed the “Care for Stroke” intervention to provide information to stroke survivors and their families. This intervention was developed using the systematic approach recommended by the MRC³, including:

- a. Assessment of the evidence base for the intervention,
- b. Assessment of the rehabilitation needs of the stroke survivors and their caregivers,
- c. Development and digitisation of the intervention
- d. Field-testing of the intervention to identify operational issues
- e. Pilot-testing of the intervention for its feasibility and acceptability in an Indian context.

This approach provided valuable information to build a framework to address the growing needs of stroke survivors and the demand for stroke rehabilitation services in India and other LMICs.

7.1 Reflections on the Research Study Methods

A mixed-methods approach was used to develop and evaluate the intervention for its feasibility and acceptability. Overall, this approach was useful in maximizing the strength of the qualitative and quantitative methods used in this research study to answer the questions that are inadequately answered by either of these methods independently. A deeper reflection on the methods used in this PhD research study will be discussed in detail in this section.

7.1.1. Setting:

Participants in the research study were recruited from a multi-speciality hospital situated in a metropolitan city of South India. We could not identify any hospitals that provided stroke services in rural areas except for CMC Vellore. Since the study site (Chennai) was the capital city of the entire state with renowned, world class facilities for health care, most of the people affected by stroke (from Tamilnadu) came to Chennai for their treatment. Of the twenty eight hospitals within India that was approached for participant recruitment (including CMC Vellore), VHS was the only hospital that provided permission to conduct this study. This permission was only to access the contact details of the stroke survivors who received treatment in the neurology (TINS) department of the hospital.

If, there were more recruitment centres, the study could have had sufficient power (sample size) to understand the results for different stroke types (Ischaemic and Haemorrhagic) and stroke severity (Minor, Moderate, Moderate – Severe, Severe). If more participants were recruited for this study, it would have been possible to stratify the study results by various demographic factors such as age, sex, education, occupation and socio-economic status. It could have also provided valuable information regarding the experience, barriers and facilitators for rehabilitation

among different kinds of hospitals in both urban and rural areas (Government, private, NGO etc.).

Most of the patient approached for participant recruitment at the hospital, did not have a CT scan or MRI done in the hospital. Generally the investigation reports remained with the stroke survivors since they had to do it on their own, outside the hospital and pay for it. Neither the findings from the radio-diagnosis nor the interpretation by a specialist was available in most of the patient reports. Stroke survivors felt that it was useful for them to keep their reports since they can meet any other doctor, showing these reports to avail their inputs. Many hospitals that were approached did not have a standardised system (electronic or paper) to record the details of the diagnosis and treatment of the stroke survivors. Given these issues, it was difficult to get the exact investigation, assessment and treatment details about the stroke survivors from records available with them and also from the hospital. Although cumbersome, this allowed the investigator to assess the stroke survivors independently.

It was also not possible to explore the penetration level of smartphones and the experience of people using smartphones in the rural areas of India. This activity would have informed the development of specific strategies for addressing the burden of stroke-related disability in rural India. However, the study covered participants within the radius of nearly 50 kilometres around the hospital that included semi-urban and some rural areas of greater Chennai. Inclusion of participants from these areas brought out key operational issues related to delayed video-streaming and poor connectivity during the field-testing phase. This allowed me to rectify the operational issues and revise the intervention.

Participant recruitment only from this urban setting might not have helped us in completely understanding the preferences given by stroke survivors to alternative medicine (Ayurveda, Yoga, Unani, Siddha, and Homeopathy) and traditional healing practices that is very common in rural areas of India. However, many stroke survivors especially those who had their family members (siblings and children) working in Chennai were shifted from their village to Chennai for treatment. Given the huge number of specialty hospitals, family members of the stroke survivors believed that the stroke treatment facilities available in Chennai may be better than facilities in their rural hometowns including those which comprise of traditional healing practices. .

The biggest advantage of this study was the setting where the entire assessments and testing took place. Stroke survivors and caregivers were assessed, surveyed, interviewed and observed in their real-life setting like home and workplace. This allowed the investigator to gain useful insights related to the felt needs of the stroke survivors and their caregivers and also their actual life after stroke. These insights have been helpful in developing a context-specific, need-based, patient-centred intervention. Also participants were recruited only after their discharge from hospital. This criterion provided an opportunity to explore the experiences of stroke survivors receiving stroke services at the hospital and also to understand how well their needs were understood and met by the healthcare providers.

Use of mixed methods approach to assessment of the rehabilitation needs helped to develop a relevant intervention, specific to the needs of the stroke survivors and their families. The quantitative survey helped the investigator understand the magnitude of the various kinds of rehabilitation needs following stroke. Conducting the in-depth interviews helped in gaining useful insights about the mechanism by which these needs arose. Participant observation

provided clarity of the operational issues related to the use of smartphones to access the ‘Care for stroke’ intervention. Expert group meetings provided valuable guidance to triangulate the information from various methods and arrive at a framework for the intervention that was evidence-based, need-specific and culturally relevant.

7.1.2. Practical Challenges

Conducting a three phased research study and completing the writing up of a thesis within the time frame of a PhD was a major challenge for the investigator. Several issues had to be considered in order to achieve this goal on time. Some of the major practical challenges that I faced to achieve the objective of this PhD are discussed in detail in this section.

7.1.2.1. Obtaining permission from hospitals

Obtaining permissions from the hospitals for participant recruitment was challenging. With the help of the supervisor and known sources, nearly twenty eight hospitals from various parts of India were initially contacted through emails. But we did not receive any positive response from most of these hospitals. As a next step, the investigator decided to meet the head of the department and higher officials of the hospitals and share the details about the research study in person. However, most of these officials did not respond to the request and only some of them provided appointments for the meeting. Even, some of these officials who provided appointment did not meet the investigator as promised. The investigator had to wait for hours together to meet these hospital officials. The investigator was unable to meet few hospital officials who gave only verbal approval and hence could not proceed forward.

Some of the hospitals requested for a fee to conduct the research study through their hospital. The fee ranged from rupees 50,000-100,000 per annum. Some of the hospitals wanted the

investigator to pay for their staff (allied health professionals) to conduct the study. Given that this was a PhD research, the investigator was unable to negotiate and get permission from these hospitals. However, the investigator managed to obtain permission from one hospital from Chennai, Tamilnadu. Permission was awarded with the condition that the investigator would not be requesting any workforce from the hospital and should provide technical support to the developmental activities of the neurology department (TINS) and the rehabilitation centre of the hospital.

7.1.2.2. Obtaining Ethics approval from the hospital

There was a significant delay in obtaining ethics approval from the hospital. To our knowledge, the reason for the delay was issues in bringing all the members of the ethics committee together for a meeting on a specific date. Several issues were raised by the ethics committee that were not directly relevant to the ethical aspects of the research study. Firstly, it was the request from the ethics committee to change my PhD supervisor – the committee wanted someone from the hospital to be my primary supervisor for the PhD. I explained the academic and funding arrangements from the Wellcome Trust – Public Health Foundation of India for my PhD including the plans for PhD supervision. Following this, the committee decided that there will be a collaborative site supervisor for onsite supervision.

Secondly, the ethics committee advised me to handover the smartphones used by the study participants to access the intervention to them at the end of the study as an incentive. But this issue was thoroughly discussed and then it was decided by the ethics committee that the DVDs of the intervention will be provided to the participants as an incentive for participation rather than the smartphones at the end of the study.

Thirdly, the ethics committee recommended that the collaborative supervisor from the hospital would be an author of all the (publishable) research papers arising from the PhD. After a long discussion, the ethics committee agreed that authorship could be given, if there was significant contribution from the collaborative site supervisor to the research paper and not just because of the supervisory role.

7.1.2.3. Delays during the conduct of the research study

There were several aspects of the research study that delayed achieving the objectives of the PhD research on time. Some of the reasons for the delays were related to

- Obtaining ethics approval,
- Recruiting the desired number of participants for all the three phases of the study
- Devising the intervention
- Developing the Web application
- Conducting the expert group meeting.

Since most of the delays were unavoidable, completion of the PhD research study and submission of thesis was delayed by four-five months.

7.1.2.4. Developing the application

The software consultants hired for developing the intervention found the content and the intervention anew and they did not have any prior experience of developing an application for health-related issues. Hence the investigator designed the web-layout and pages for the intervention. The investigator designed the logo, provided the architecture for web-designing and various kinds of interfaces/icons that are disabled-friendly. The investigator developed the content (script and visuals) for the application. The real challenge was to make the software application developers understand that, as this is not something that they usually do for other

sectors (business, accounting, marketing, engineering etc.) and help them deliver what was required. The difficulties experienced by a stroke survivor were well-explained to the application development team and the investigator was physically supporting the technical team during the entire period of application development.

7.1.2.5. Digitizing the content of the intervention

Similar to application developers, it was also very difficult for the videographers to shoot what was required and edit efficiently. For example during a shooting about positioning a stroke patient, they were interested in shooting the entire frame (home, bed, stroke survivor and the caregiver in one frame), rather than having a frame that explains where to hold, how to move the stroke survivor and how to support (caregivers position, Stroke survivor position, hand movements etc.). The same problem was seen even during editing. Also the videographers found these kinds of film making with intricate details to body and limb movement anew. However, the investigator wrote the script, sequenced the activities and directed the shooting himself. He also worked along with the editors to explain the visualization and flow of the activities/tasks during digitization.

7.1.2.6. Handling the expectations of the participants

One of the biggest challenges during the entire PhD study was to handle the expectations of the participants. One of the major questions from the stroke survivors and the caregivers was about getting completely alright as before. There was huge expectation from the participants that a stroke survivor will be alright after they receive few weeks of physiotherapy. The stroke survivors and the caregivers in most instances were provided with detailed information about recovery following stroke in the section of intervention. Another question was about the details of rehabilitation centres and stroke treatment centres close to their home and also apart from the

hospital where recruitment took place. Since there wasn't many multi-disciplinary stroke rehabilitation centres within Chennai it was very difficult to refer stroke survivors to a centre that is close to their home or that is multidisciplinary. However, information about some of the well-known rehabilitation centres within Tamilnadu and India was provided to them.

7.1.3. Researcher's perspective

The position of the principle investigator in the conceptualisation and conduct of the entire study was very crucial to the success of this PhD research study. The investigator was basically from Chennai, India. He was initially trained in occupational therapy with the experience of treating people with neuropsychiatric conditions, especially brain injury (including stroke) and spinal cord injury. His post-graduate training was in public health with an elective specialization in health program management. He had nearly thirteen years of experience practicing, teaching and conducting research in the field of disability and rehabilitation from various parts of India, Nepal and in the U.K.

7.1.3.1. About the conception of the research study

The investigator worked as a stroke specialised occupational therapist in the U.K prior to commencing his PhD. He was a part of an early supported discharge team that provided out of hospital services for people affected by stroke. In the early supported discharge service, stroke survivors admitted in the hospitals were discharged home if they were medically stable and the rehabilitation team provided stroke services to the stroke survivors at their home. Having worked as a part of this team for two years, the investigator was motivated enough to translate this concept to a LMICs setting like India. Given the lack of resources, infrastructure and policies for provision of stroke care; he intended to develop a workbook based intervention with the inputs from all the disciplines involved in stroke rehabilitation. The question that was put forth by

experts and colleagues from the field of disability and rehabilitation was about the availability of a standardised rehabilitation intervention for stroke survivors in any LMICs including India. Since there wasn't any intervention exclusively for stroke survivors, the investigator decided to develop an evidence-based, culturally relevant, need-specific, patient-centred intervention for the stroke survivors in India.

7.1.3.2. Conceptualising the methods for empirical exploration

Although the investigator was trained and experienced in prescribing a rehabilitation intervention for stroke survivors in the context of both HICs and LMICs, he did not depend on his expertise to develop the intervention. He preferred to be a passionate researcher enthusiastically striving to seek answers for his research question without being biased. With tremendous guidance from the supervisors and based on the recommendations from MRC on the development of complex interventions, the methods for developing this intervention was conceptualised and carried out.

7.1.3.3. Steps taken to prevent investigator bias during research study

Development of the 'Care for stroke' intervention was phased and systematic. Two systematic reviews were conducted by the investigator rather than a general literature review. Unlike general literature review, systematic review rules out potential bias by having more than one reviewer. The co-reviewer in a systematic review may or may not agree to what was reviewed by the investigator alone. There was also a third reviewer to resolve conflicts when there was disagreement between the investigator and the co-reviewer in these two systematic reviews.

In terms of the rehabilitation needs assessment study, participants who got discharged from the hospital and who lived at home/community were selected. Conducting the needs assessments in a hospital setting would not have provided the true picture of the situation. For instance, a

participant might have received one or the other kind of services, so they would have felt there is no specific rehabilitation need within the hospital. Secondly, participants cannot talk about something that they have not experienced. During the pilot testing of the study tools, a stroke survivor said “Only when we go to our home – we will be able to say what we need”. Thirdly, responses from participants would have been based on an assumption that if they do not give correct answers, they will not get proper care from health professionals at the hospital. This may lead to a biased response. Thus the needs assessment study was conducted in the home environment. In fact, the department medical officers assessed the participants for their eligibility to participate in every phase of the study. In this way, efforts were made to obtain reliable and unbiased answers for the research questions.

The investigator did not stop with a single method to explore the rehabilitation needs of the stroke survivors. The magnitude of the unmet needs was assessed using a survey and the reasons behind the magnitude of needs were explored in detail through in-depth interviews among providers, affected individual and the caregivers. This had helped in triangulating information obtained from participants by both these methods. It also provided clarity about why certain needs are high and why some are low.

Although the needs assessment survey was conducted by the investigator himself, it provided an unbiased answer to this research question. Needs were related to information than rehabilitation or activities of daily living. Importantly, the investigator arrived at the best content for the intervention only through an expert committee and not just by himself. The framework and content of the intervention was decided by the committee rather than the investigator.

The intervention was tested at two levels and refined accordingly. During field-testing, the investigator used direct observation techniques rather than just the self-report of operational issues experienced by the participants. This provided an opportunity to identify more issues and revise the intervention accordingly. The revised intervention was again shared with the expert committee to get their approval before pilot-testing. Feasibility and acceptability of the finalised intervention was assessed through a satisfaction survey during pilot testing. In addition, the intervention was also developed with an administrator module where tracking the utilisation patterns of the intervention was possible. This helped in authenticating the results of the pilot-testing.

7.1.3.4. Optimization of the researcher's expertise for the study

There were several ways in which the researcher's expertise was optimized for the conduct of the researcher study. The investigator's expertise was very helpful in finalizing the presentation of results and choice of outcomes in the systematic reviews. Given the heterogeneity among the studies related to the epidemiology of stroke in India, the investigator decided to do a narrative analysis. Most of the challenges while conducting this systematic review were also documented during the review. These challenges in understanding the epidemiology of stroke in India was written as a research paper which was the first paper that was published from this PhD. For the systematic review on the effectiveness of educational intervention for people with stroke, disability and dependency was the choice of outcomes. In a generic review, the outcomes might have been knowledge, attitude and practice parameters. This had helped in developing an intervention with evidence from literature that was targeted towards management of disability following stroke.

In terms of the needs assessment study, the investigator was able to gain an in-depth understanding about not just health care but also about rehabilitation and management of disability at the hospitals and also at domiciliary locations with his expertise. For example, couple of additional interviews with stroke survivors was conducted to understand the meaning given to the statement ‘I need to stand and walk – that’s my priority’ – which meant – to be able to independently participate in family and social roles’. With these useful insights, the investigator was able to come up with a framework for bridging the gaps in access to stroke rehabilitation services at the end of this study.

Although the theoretical content of the intervention was finalised by the expert committee, it was the experience of the investigator that helped in digitizing the complete intervention. Unlike a movie or a documentary about stroke and how to manage it, the intervention has nearly sixty three videos of 2-3 minutes, organized in five major sections. Some of the information such as ‘engaging in activities of daily living’ was the most seen videos by the stroke survivors. It included single-handed techniques to independently perform daily activities like dressing, brushing, eating after a stroke which was not known or never seen by even some of the health professionals in India. The investigator was able to thoroughly reflect on his experience (working in resource poor setting and helping people with disabilities get back to their everyday activities) in the intervention. In the intervention, he had also managed to provide very useful directions for the stroke survivors and caregivers while they recover. For example, how to sleep on the affected side; where the supports should be provided while helping someone to walk etc.

Overall, the investigator had clearly conceptualized about the entire methodological process of the study and had taken several steps to ensure that the intervention was developed based on evidence and expert guidance rather than on his own experience and judgements. He had also

optimized his skills to obtain good quality of evidence in the field of development and evaluation of complex interventions.

7.2 Summary of Main Research Findings

7.2.1. Epidemiology of Stroke in India

The first step towards the development of the ‘Care for Stroke’ intervention was, understanding the epidemiology of stroke in India. Lack of reliable reporting mechanisms and heterogeneity across existing epidemiological studies on stroke made it difficult to obtain a single accurate estimate of the magnitude of stroke in India⁴⁻⁵. Therefore a systematic review of all population-based epidemiological studies on stroke in India was first conducted.

Results from the systematic review revealed that India is experiencing a silent epidemic of stroke. Findings from this review were in line with the stroke estimates in LMICs reported in the Global Burden of Disease study⁶. The cumulative incidence and prevalence of stroke in India during the past two decades in different parts of the country were much higher than those reported from High Income Countries⁶⁻⁷. These findings points to a growing burden of stroke and stroke-related disability in India⁸⁻⁹. The magnitude of the problem warrants development of population-wide rehabilitation interventions for addressing the unmet needs of those affected.

7.2.2. Educational Interventions for Stroke-Related Disabilities

Given the dearth of evidence on the subject and the pressing need for information among those affected, I conducted a systematic review of educational interventions for rehabilitation following stroke. Available evidence suggested that active, patient-centred educational interventions could reduce the extent of disability, enhance participation and improve quality of life of stroke survivors. The review established that educational approaches involving active

learning were more likely to be effective in terms of improving the quality of care¹⁰⁻¹¹. Meta-analysis of such educational interventions has also shown significant positive effects when multiple strategies were used for patient education rather than a single technique¹².

Conducting the systematic review also provided valuable information on the core components for inclusion in the intervention, including information dissemination, home-exercise programmes, expert guidance and the importance of the activities of daily living. Moreover, the review helped in designing specific content and facilitated understanding of various educational methods and communication media through which the intervention could be shared.

7.2.3. Rehabilitation Needs of Stroke Survivors in the Community

Compared to HICs, there is a paucity of information about the rehabilitation needs of stroke survivors in India⁷⁻⁸. Therefore, it was important to assess the perceived rehabilitation needs of stroke survivors in India as a component of this research as this was envisaged to provide valuable information for developing a patient-centred rehabilitation intervention.

Findings from the needs assessment indicated widespread need for rehabilitation services among stroke survivors and their caregivers. To our knowledge, this is the first needs assessment study of this sort carried out in India. However, the findings of two other studies on rehabilitation needs assessment carried out in LMICs were similar to ours, with information needs identified as the first priority for stroke survivors in both^{9, 13}. Although the context is very different, the findings from our study were also similar to the results of several needs assessments conducted in HICs¹⁴⁻¹⁹. Severity of disability and rehabilitation need was found to be higher among those stroke survivors who did not access post-stroke rehabilitation¹⁵⁻¹⁶. Family and caregiver support was considered to be an important facilitator in meeting the

rehabilitation needs of stroke survivors¹⁴. As expected, the needs assessment study provided directions for developing appropriate content for the intervention. It also confirmed the importance of caregiver support in stroke rehabilitation.

7.2.4. ‘Care for Stroke’ Intervention

Findings from the systematic reviews, as well as the assessment of rehabilitation needs and guidance from experts in the field of neurological rehabilitation facilitated the development of the ‘Care for Stroke’ intervention.

Available evidence in India showed that there is a good distribution of smartphones²⁰⁻²². It is estimated that the number of smartphone users globally will surpass two billion in 2016, amounting to more than a quarter of the world’s population²⁰. China and India are estimated to dominate the smartphone market with over 500 million and 200 million smartphone users by 2016, respectively²⁰. This exponential growth provides an opportunity for development of many mHealth applications. Independent think tanks have reported that there are nearly 17,000 mHealth applications available globally²¹ and that nearly 52% of smartphone users utilise their phones for looking at health or medical information²². Given the tremendous advancements in mHealth and phenomenal growth in smartphone utilisation, a web-based, smartphone-enabled rehabilitation intervention like ‘Care for Stroke’ seems an appropriate and feasible strategy to address the needs of stroke survivors and bridge the gaps in access.

The strengths of the smartphone technology (calling options, Skype, WhatsApp, Twitter, Facebook, SMS, GIS, cloud) inbuilt in the intervention can be combined with existing rehabilitation services to sustain the gains obtained by the stroke survivor during recovery in the hospital and in agreement with the continuum of care, especially outside the hospital

environment. This strategy could prompt the active participation of the affected individuals and their families during recovery. It could also promote effective communication between providers and service seekers and hasten the process of recovery post-stroke. Tapping into the strengths of smartphone technology may also provide tremendous opportunities for service providers and managers to virtually monitor patient improvement and track progress in the use of the stroke rehabilitation programmes in real-time. Such a stroke intervention for enhancing acute stroke care in Australia has been shown to increase the rate of thrombolysis, reduce the timelines for clinical processes and result in favourable discharge outcomes²³.

The ‘Care for Stroke’ intervention is web-based and smartphone-enabled. Its content is predominantly educational in nature, focussed on the management of physical disabilities following stroke in the actual environment (home) of the affected individuals. The intervention is in a digitised audio-visual format that can be used by stroke survivors, with or without support from their caregivers at home. Smartphone-based self-management interventions are considered to be a viable option for reducing the substantial cost involved in managing chronic diseases²⁴.²⁵ Smartphone-enabled disease management interventions led by clinicians have also been shown to be beneficial for patients in recent studies²⁴⁻²⁵.

Currently, there are only a few mHealth applications for stroke survivors, predominantly related to identification of stroke and in compensating cognitive-communication problems following a stroke. Smartphone applications used in stroke rehabilitation include the Dr Droid application, which helps therapists to administer and track upper-limb exercises for stroke rehabilitation²⁶, and the Think-FAST application, which includes stroke prevention information and a list of stroke unit locations in Australia²⁷.

To the best of my knowledge, ‘Care for Stroke’ is the only smartphone-enabled intervention that is primarily focussed on the rehabilitation aspects of stroke which provides specific information related to the management of stroke-related disability. The intervention includes information about stroke and the ways to manage stroke-related disability. It presents a practical demonstration of functional post-stroke exercises to acquire the functional abilities necessary to perform everyday tasks, adaptive techniques to perform one’s own daily activities independently and a specific section on assistive devices that could enable participation of the stroke survivors in their daily tasks. The intervention is designed in such a way that it can be either self-delivered or utilised with support from caregivers.

7.2.5. Evaluation of the Intervention

It was important to test the feasibility and acceptability of any new intervention before it becomes widely available. Therefore, we conducted a study to assess the feasibility of using such an intervention as a pilot. Findings from the pilot showed that the ‘Care for Stroke’ intervention was feasible and acceptable in the Indian context. In particular, because the intervention was culture and language-specific, relevant to the needs the stroke survivors, provided in a digitised audio-visual format and contained actual illustration / demonstration of exercises and activities that can be practised at home.

The next step is to evaluate the effectiveness of the ‘Care for Stroke’ intervention in India. A recent pilot trial focussing on family-led rehabilitation of stroke survivors established the feasibility of conducting large-scale rehabilitation trials in India²⁸. Going forward, it is also important that the intervention be assessed for its effectiveness in other countries where access to rehabilitation services is poor and the information needs of the stroke survivors are largely unmet²⁹.

7.3. Strengths and Limitations of the intervention

The biggest strength of the intervention is that it does not require skilled professionals to provide information about stroke and management of stroke-related disability. Thus it closes the treatment gap for post-stroke rehabilitation in contexts where there is limited resource for rehabilitation. Multi-disciplinary, patient-centred stroke rehabilitation services are hardly available to stroke survivors in India. Let alone community-based services, it is not available even at most hospitals in India. Given this situation, an intervention like ‘Care for Stroke’ provides multi-disciplinary inputs for the stroke survivors to manage their physical disability following stroke. For example, it includes information about exercises, functional skills, assistive devices, everyday living etc. Since the intervention is technology-driven, it provides every opportunity for the affected individual and their family to seek advice about their problems from the health providers through SMS, Skype and other services. The intervention empowers stroke survivors and their caregivers to take appropriate decisions during recovery and has options for seeking support from the health care providers. This kind of right-based empowerment (the patient empowered to take decision) of stroke survivors and their family to healthcare is potentially expected to close the treatment gap for access to stroke rehabilitation in India.

‘Care for Stroke’ intervention is specific and relevant to the needs of stroke survivors, especially in a south India context. The intervention was developed in Tamil, which is the vernacular language used in the southern part of India. The actors who performed as stroke survivors resembled persons from Tamilnadu or south India. The content of the intervention was oriented towards functional goals expected from the rehabilitation process and stimulated participation of the users in their activities of daily living, such as feeding, bathing, dressing, transfers and mobility. The intervention also included one-handed techniques to perform daily living activities

to motivate and enhance therapeutic recovery, especially amongst those with retained use of one upper limb only.

The intervention also comprised of many culturally-specific therapeutic activities, including wearing a saree or dhoti (traditional clothing), grooming and bathing. Almost all of the material and devices used in the therapeutic training were objects commonly used at home. The intervention encouraged stroke survivors and their families to use commonly available objects (e.g. pillow, chair, shirt, saree, toothbrush, etc.) to manage their post-stroke problems, without requiring users to buy expensive therapeutic equipment for their home-based care. In addition, the intervention included a separate section on adaptive / assistive devices that are locally available or that can be tailor-made to facilitate independent performance of daily activities (e.g. universal cuff, guarded plate, two-handled cups, Velcro-attached shirt and saree).

‘Care for Stroke’ is a technology-based intervention. It is feasible to share or disseminate information to a large number of stroke survivors in real time through this technology. Because it is web-based, the intervention can be viewed on any kind of telecommunication device, including smartphones, laptops, desk computers and smart televisions connected to the Internet. Being smartphone-enabled, the intervention remains portable and allows users to watch the content any number of times and from any geographical location just by touching the screen. It will also be easy to update and upload more information as new techniques are developed for stroke rehabilitation and when new needs for rehabilitation are identified.

An advanced and important feature of the intervention is its capacity to monitor usage. The web-application allows virtual monitoring of real time end-user utilisation patterns, including time spent on the application, contents engaged and the geographical location of end-users. The

monitoring feature of the intervention can also help to identify sections that are not being used, improve those sections and refine the intervention continuously.

Unlike existing methods of post-stroke rehabilitation information provision (text format and workbooks), 'Care for Stroke' provides information in a digitised, demonstrable audio-visual format. Learning became comfortable, comprehensible and reflective when the intervention was in a digitised video format³⁰⁻³¹.

Whilst the intervention can be accessed autonomously by stroke survivors, there is a twofold advantage when they are supported by their caregivers in accessing the intervention. Firstly, the intervention assisted both stroke survivors and their caregivers to be well-informed about post-stroke rehabilitation. Subsequently, it provides an opportunity for joint decision-making, which may hasten the recovery process. This is because there is immense therapeutic value when families and caregivers understand and support post-stroke recovery¹⁷. Secondly, since the intervention is carer-supported, it limits the need for skilled professionals to support the stroke survivor in person and, hence, allows scaling up of post-stroke rehabilitation and care.

A major limitation of the intervention was the requirement of a smartphone with internet connectivity to access the intervention. Although most of the stroke survivors and/or their caregivers who participated in the study owned a smartphone, all were not able to afford sufficient 3G data allowance to access the intervention. This was the primary reason for discontinuation of the intervention by pilot participants. The intervention was streamed online purposefully, so as to monitor utilisation of the application in real time and assess feasibility. There are several options to overcome this limitation. First, the intervention could be loaded onto a Secured Digital (SD) memory card that could be used without an internet connection.

Secondly, an advanced software application could be developed and merged with the present web-based version to allow users to access the content offline.

Although possible, ‘Care for Stroke’ is not currently designed to replace the concept of contemporary, individually-tailored stroke rehabilitation service provided by a therapist or a multi-disciplinary team in a therapeutic setting. In the context of HICs, where there are sufficient resources for rehabilitation, ‘Care for Stroke’ intervention is expected to be used only as an adjunct to the therapeutic services available to stroke survivors. This is because; people generally prefer to be treated by health professionals in person, especially when they are available. Thus, in the context of HICs, ‘Care for Stroke’ can help link the stroke survivor receiving hospital-based care to community-based care. It can also enhance the continuum of care even after hospital discharge through virtual follow-ups, provision of updates about recent treatment advancements and remote monitoring of the stroke survivors.

From a mHealth perspective, ‘Care for Stroke’ is not a ‘one size fit for all’ if it is delivered through a health professional or a trained CBR worker. It is possible to tailor the intervention according to the needs of the stroke survivor, if there is a trained/expert provider to support. For instance, a CBR worker or a stroke liaison worker could provide this intervention to the stroke survivor in a much more organized way and could also tailor the intervention according to the needs of the stroke survivor.

On the other hand, the intervention can also be improvised into a ‘Brain-Computer interface’ where brain signals are used to control the environment, object and activities around us. In this case, brain signals from stroke survivors can be used to access the required information about management of physical disability from the Smartphone. Thus, it could become a self-

management intervention. However, in a country like India and in similar contexts where there is very limited access and availability of even uni-disciplinary stroke services, 'Care for Stroke' intervention has the potential to provide multi-disciplinary inputs for management of physical disabilities following stroke. It also has the potential to close the treatment gap for stroke rehabilitation in similar contexts.

The content of the 'Care for Stroke' intervention is restricted to stroke and physical disability related to stroke. The intervention doesn't cover the other kinds of disability following a stroke like issues with cognition, perception and socio-emotional aspects. The expert committee for the development of content for the intervention felt that the effects of these kinds of disabilities are diverse. For example, cognitive-perceptual disabilities can include inattention; poor reasoning skill and problem solving skills, loss of memory and judgemental skills etc. They also felt that it requires highly specific inputs from specific disciplines depending on the extent of impairment and its impact on the life of a stroke survivor. For example, a person with poor memory in calculations aiming to get back to his bank job will require the help of an occupational therapist while an orator who forgets the conjunctions while speaking will seek help from a speech therapist. Since including these aspects into the intervention was time and resource intensive, the investigator was advised to focus on only physical disability aspects of stroke within the scope of this PhD. However, the expert committee suggested that this must be incorporated during future revisions and improvisation of the intervention.

India is a large country, with people from diverse cultures, speaking different languages and with varied lifestyles. The 'Care for Stroke' pilot intervention is currently confined to stroke survivors who can understand Tamil and who are familiar with the cultural practices in Tamilnadu, India. If the intervention is considered acceptable in other states within India or in other countries,

there will be a need to develop numerous additional versions of the intervention based on the language and cultural characteristics of users, both nationally and globally.

The ‘Care for Stroke’ intervention was developed as a part of a doctoral research study and, hence, the research fund granted was not sufficient to develop an advanced mHealth intervention addressing all current limitations. However, priority will be given to rebuilding the intervention with an advanced mHealth platform to bridge present limitations in the near future, if additional funds become available. Another important limitation of the intervention is that it primarily addresses the physical rehabilitation needs of the stroke survivors and not their wider needs, such as for inclusion in employment, enhanced social participation and so on.

7.4. Strengths and Limitations of the Research Study

A multi-phased, mixed-methods approach was adopted for designing, developing and evaluating the ‘Care for Stroke’ intervention³². This systematic approach facilitated a comprehensive understanding of the necessary inputs to develop a complex rehabilitation intervention. Each phase of the intervention development process answered specific research questions³². Adopting a single methodological approach would have been inadequate to obtain answers to these research questions and a deeper understanding about it³³. Employing a mixed methods approach was very useful in developing the intervention to answer these questions in a comprehensive way.

The combination of quantitative and qualitative methods used complemented one another and broadened the interpretations and conclusions drawn from each phase of the research study. Principles of qualitative analysis were integrated and applied to synthesise evidence narratively (qualitatively) from the systematic reviews³³. Triangulation of information from the needs

assessment study confirmed the results obtained from the quantitative survey and qualitative interviews. Subsequently, qualitative findings from the needs assessment provided a broader understanding about the barriers and reasons for the substantial needs reported by the participants in the quantitative survey. Quantitative and qualitative findings from the studies were combined and presented together, rather than as a standalone method, thus optimising the value of the mixed methods approach adopted.

This study also employed a mix of different methods of quantitative and qualitative assessments, such as a survey, structured interviews, participatory consultation, direct participant observation, in-depth interviews, patient-experience survey and assessment of clinical outcomes. Combining these diverse methods assisted in expanding the scope of the extrapolation of the study results to countries with a similar context. It also generated new insights that could potentially assist in bridging the gaps in access to stroke rehabilitation services in India and in countries with a similar context. I believe that this multi-phased and mixed methods approach helped us in identifying an intervention which was evidence-based and tailored to the felt needs of stroke survivors and their carers.

Given that the research was conducted as a part of a PhD programme, time constraints and limited funding were major challenges experienced. The principle investigator (SK) undertook the entire responsibility of collecting, analysing, interpreting and integrating the data. However, the principal investigator worked very closely with his supervisors and other domain experts in developing the study design and interpreting the findings.

Only one hospital (a tertiary hospital with a neuro-rehabilitation centre in a metropolitan city) provided permission to recruit participants for the research study. This was a significant

limitation, as the clientele visiting this hospital was from the middle and upper-middle socioeconomic strata. Recruitment of purposively-selected participants from one particular hospital for the quantitative assessments also resulted in a sample size that was inadequate to perform stratified analysis and provide detailed inferences on different sub-groups of stroke survivors and caregivers in these assessments.

In addition, since participants for the study were recruited from only one setting, generalisability of the findings has limitations. Given the time constraints, a comparison group (for example, either a placebo or another intervention) was not included. It was also not possible to evaluate the effectiveness of the intervention within the scope of the study for the same reason, but this could be a focus for future research. Unlike a single approach (quantitative or qualitative) for assessment, using a mixed methods approach created an additional time burden.

Moreover, the criteria for participant inclusion were very specific and did not include chronic stroke survivors with severe stroke and with speech-language difficulties. However, the investigator had appreciated the subtle cognitive changes that could interfere with the use of Smartphones among the eligible participants. This was one of the important reason for the inclusion criteria to also include a primary caregiver living along with the stroke survivor. Also that is why the intervention is not just smartphone-enabled but also caregiver supported. A severe stroke-specific version and also versions that include information about management of cognitive-perceptual and psycho-social problems following stroke would be necessary to meet all kinds of needs of all stroke survivors.

This study did not look at the feasibility of the ‘Care for Stroke’ intervention in a rural context of India. Though the investigator initially attempted to recruit participants from various parts of India including the rural areas, he was able to obtain permission only from one hospital situated in a metropolitan city. Thus the experience of stroke survivors both in terms of accessing stroke care and also using smartphones were not covered in this research study.

The aspect of health seeking behaviour among people living in rural areas, especially following a condition like stroke is still unexplored in India. It was believed that stroke survivor in rural areas usually seek care from traditional healers and Ayurveda, Yoga, Unani, Siddha and Homeopathy (AYUSH) practitioners. Exploring these aspects could inform the development the ‘Care for Stroke’ intervention that is inclusive of various other health disciplines involved in stroke care. It could also provide strategies for developing sustainable solutions to the stroke survivors living in the rural areas of India. Given that 70% of India’s population resides in rural areas, it would have been useful if this study could have covered the stroke survivors living in rural areas too. However, future studies on the ‘Care for Stroke’ intervention will definitely focus on this aspect and explore empirical solutions to management of physical disabilities following stroke in rural areas.

A similar study with a similar focus would have been a multi-centric and multi-country study, if it was not a PhD study and if it was adequately funded. The investigator would like to take this opportunity to confess that this study would have definitely been much more informative and rigorous if he was provided with sufficient time and funds. He also would like to confess that it was very difficult to obtain permissions from the hospital and recruit participants as expected in the initial stages of the PhD. Instead of a student investigator, if it was a renowned and leading researcher from a famous organization, he would have received support from more hospitals

and the study would have been completed as planned. In general, the amount of recognition and support given to a student researcher is much lesser when compared to celebrated researchers with wider networks from illustrious institutions.

In addition, if there was a research study on stroke rehabilitation conducted by a renowned researcher or institution on a similar topic, that study would be given priority. India's largest multi-centre clinical trial on stroke rehabilitation called the 'Attend trial' was conducted exactly during the same time this study was conducted. This could be one reason why some of the key hospitals which participated in the 'Attend trial' may not have been enthusiastic about getting involved in another stroke study.

Since the principal investigator was the only person who collected the data, there is scope for the investigator's personal biases to have influenced findings. The investigator took every step possible and available to minimise the bias and ensure trustworthiness of the data collected, especially through qualitative methods.

Credibility of the studies conducted and the data collected from these studies was established in various ways. Firstly, the investigator adopted specific research methods that are strongly grounded in the principles of quantitative and qualitative investigations for specific purposes³⁴⁻
³⁵. Literature reviews were conducted systematically. Both a quantitative survey and in-depth interviews were conducted in combination to gain a deeper understanding of the rehabilitation needs of the stroke survivors. To identify operational difficulties, the investigator used a direct observation technique as well as through self-reports in interviews. Feasibility and acceptability were assessed using both a structured survey and patient experience interviews.

The investigator used a mix of methods to triangulate information and ensure validity of the data collected³⁶. The investigator also used certain tactics to encourage honesty among participants while answering questions, as suggested by existing literature, such as an iterative questioning technique³⁷⁻³⁸. The approach to presentation of the qualitative data was also more emic (what stroke survivors and caregivers thought and expressed about their problems) than etic (what the investigator perceived and understood)³⁹⁻⁴⁰. Overall, considerable effort was made to demonstrate that the inferences obtained from the research study were not idiosyncratic interpretations.

7.5. Implications of the Findings for Practice in a Global and Indian Context

The ‘Care for Stroke’ intervention has several implications for clinical and public health practice globally. In the global context, this intervention could be a useful adjunct to augment the outcomes of existing stroke rehabilitation interventions. This intervention could be provided to the stroke survivor at many different points of contact (e.g. hyper acute stroke care, acute care, post-acute rehab, community rehab and long-term follow-up) in the existing standard clinical and operational pathways for stroke rehabilitation. This would enable stroke survivors and their families to be informed about their problems and assist them in taking proactive decisions about their recovery along the continuum of stroke treatment and rehabilitation spectrum.

In the context of India, where resources for rehabilitation are limited and the gaps in access to rehabilitation services are very wide, the ‘Care for Stroke’ intervention has the potential to revolutionise existing approaches to stroke rehabilitation. Introducing this intervention systematically to stroke survivors and those at risk of stroke during their first point of contact in any government or private health facility could create awareness about stroke and its consequences. It could render useful information to those affected to reconcile and accept stroke-

related disability. It could also help them understand more about the essential steps to be taken and engage more actively in the recovery process.

The intervention provides an opportunity to sensitise affected individuals and their families about the importance of multi-disciplinary, functionality-oriented, need-based rehabilitation to hasten the recovery process. On the whole, being aware and gaining knowledge about stroke and the recovery process can empower stroke survivors and their families to take appropriate decisions to manage stroke-related disability. It can also help those who are at risk of stroke to take appropriate measures to prevent or minimise the consequences of stroke.

The intervention capitalised on the strengths of technological advancements in India that could be judiciously used by clinicians, public-health practitioners and policy makers to compensate for the existing resource limitations for stroke rehabilitation. Use of a web-based intervention like ‘Care for Stroke’ could cut the cost incurred for transport and travel to obtain stroke-related information/services. Stroke survivors and their families could uninhibitedly gain insights about their disabling problems and the solutions to it in real-time. Since the intervention is smartphone-enabled, the advantages of telecommunication applications (Skype, Whatsapp, SMS, Facebook, and Twitter) can be tapped to ensure that evidence-based rehabilitation advice and support is virtually available for those affected from experts in health facilities at an affordable price.

‘Care for Stroke’ intervention could also be considered an exemplary model for interventions that aims to bridge the barriers to access healthcare and rehabilitation. The web-based platform for the intervention enables it to reach the groups which cannot be easily reached or covered geographically. Any geographical location with internet connectivity could be utilised to

implement this intervention. Given that this is smartphone-enabled, anyone with a smartphone and internet connection can access this intervention irrespective of whether they are rich or poor. It was evident that about 90-95% of the stroke survivors' family in this research study had at least one smartphone with them. This was irrespective of their socio-economic status. Similarly, the content of the intervention was designed to be watched rather than read. Therefore the users don't have to know to read in order to access the intervention. Anyone who understood the local language (spoken) was able to understand from the intervention. Hence the 'Care for Stroke' intervention is designed in such a way that it can be accessed by the hard-to-reach population not just in terms of their geography but also their socio-economic and literacy status.

Disseminating the prospects of this intervention could sensitise healthcare providers to the importance of information provision as a part of treatment. It could help health professionals conceive alternative strategies for the provision of stroke-related information and rehabilitation to those in need. If health professionals could integrate this intervention into their current practice, this intervention could also be a precursor to development of organised multi-disciplinary pathways for rehabilitation.

Accumulating evidence on the intervention alone is not enough to bridge the gaps in accessibility to stroke rehabilitation services. Evidence from the research studies on the intervention should be translated into policy and practice. In India, there is only one combined national programme for stroke. It is called the National Programme for Prevention and Control of Cancer, Diabetes, Cardiovascular Disease and Stroke (NPCDCS). This programme is implemented through the Non-Communicable Disease (NCD) units located in the government tertiary hospitals in every district in the state. Although the research findings of this intervention would be disseminated to the scientific community and health professionals through various

sources, sharing the study findings with the mission director, programme managers and policy-makers of the NPCDCS programme is of immense importance. This would enable policy-makers and programme managers gain more knowledge about interventions such as ‘Care for Stroke’ and potentially integrate them within the existing health programme (NPCDCS) if found to be effective.

Scaling-up of the intervention also becomes less difficult and more legitimate if policy makers are cognisant about the intervention. This would enable them to invest in future research on the intervention and promote the planning and implementation of pathways and policies inclusive of this innovative mHealth intervention. Thus, advocating and lobbying for the ‘Care for Stroke’ intervention to be integrated within the existing national programme that caters to the entire population of the country becomes extremely useful to achieve what was envisaged.

However, one must not forget that this intervention will induce digital divide and health inequalities if the users are left without any meaningful training, technical support and encouragement to use the technology for accessing the intervention⁴¹. It is now globally recognized that growth of the digital technology is rapid and vast⁴². It is also recognised that this immense growth in digital technology might create a digital divide between those who have access to the technology and those who do not. Globally, this disparity of access to digital technology (including Smartphones) has given rise to group of people who are digitally disadvantaged⁴². From the perspective of mHealth, it is very important to take this digital divide into account. This is because, the amount of information on health available from internet sources are huge⁴³.

Furthermore, the divide is not just digital it is also technological in terms of the great gaps in infrastructure, especially in LMICs⁴⁴. There is a strong divide in the content too; Lots of web-based information is not relevant to the real life needs of people⁴⁴. In addition, available information is usually in English and mostly the voices and views heard through this information comes from HICs⁴⁴. These disparities are bound to create health inequalities worldwide. But there are some proponents who claim that mHealth interventions could be a potential solution to the bridge these gaps⁴⁵.

Bridging the digital divide and the subsequent health inequalities is possible only when robust communication infrastructure and health communication/information resources are equitably distributed⁴⁵. Unless there is an understanding from health and technology professionals that there are many people outside the mainstream of digital revolution who cannot capitalise on the mHealth resources that could impact positively on their health, it is not possible to close the divide and promote equitable healthcare. There are various issues beyond access when it comes to a mHealth intervention for people with disabilities. Accessing health information from home is not similar to access from office or school. There are users from different locations, with different level of skills and familiarity to interpret health information through mHealth interventions. Hence it is absolutely important to transform 'Care for Stroke' into an intervention that provides meaningful access to information related to management of physical disabilities following stroke.

7.6. Future Research Needs

There is a paucity of global evidence on therapy-based stroke rehabilitation, especially in long-term care⁴¹⁻⁴². Available evidence shows that there is no single physical rehabilitation approach that is more effective than combinations of care⁴³. Provision of information to stroke survivors

and caregivers has been shown to improve functional outcomes⁴⁴. However, the best way to do this is still unclear. Though mHealth strategies have developed various solutions to meet the needs of stroke survivors, the best way to utilise this approach in stroke rehabilitation is also still unclear⁴⁵. There is insufficient evidence for tele-rehabilitation services⁴⁶. This context provides a strong grounding for rigorous research on the ‘Care for Stroke’ intervention.

Investigating the intervention effectiveness as a priority would provide immense insights for planning, implementation and the potential scalability of the intervention, especially in countries with limited resources. Given the methodological quality of the available evidence⁴³⁻⁴⁶, there is a pressing need to conduct a rigorous (randomised, double-blind, controlled, sufficiently powered) multi-centre, large scale clinical trial to demonstrate the effectiveness of the ‘Care for Stroke’ intervention in the near future.

Methodologically, future trials of the ‘Care for Stroke’ intervention could have randomised allocation of participants. It could use a comparison group (most likely standard care) to evaluate clinical effectiveness and cost-effectiveness. This trial could also use standardised outcome measures related to disability, functional abilities and quality of life, which would be the primary outcomes. Given the feasibility of the outcome measures to detect minimal difference within one-month follow-up in the pilot-testing, future trials could have follow-up at three, six and 12-month to detect any sizeable difference between the intervention and the control group. The follow-up assessment could be done by blinded assessors.

Given the development and feasibility of the intervention in an Indian context, it would be worth conducting the first multisite trial in India before carrying out any multi-country trials. If successful in India, then a modified international version of the intervention would have to be

developed and trialled globally through formative research. This would help in customising the intervention according to the context for rehabilitation in different countries and establish the validity of the intervention globally. If the intervention is found to be ineffective, then it needs to be revised and re-tested accordingly. In the future, the intervention could also be combined with other treatments (e.g. hospital care) to determine an optimal package for addressing the rehabilitation needs of stroke survivors experiencing various types of stroke and various degree of disability following any kind of brain injury.

The ‘Care for Stroke’ intervention provides useful insights for experts in the field of disability and rehabilitation to envision similar interventions for other disabling health conditions, like cerebral palsy, spinal cord injury, degenerative disorders of the brain, cardiopulmonary problems, schizophrenia and mood disorders. Although the pathophysiology of these conditions is dissimilar, the disability caused by these conditions and the impact of the environmental context on disability are often comparable.

7.7. Conclusions

An increase in the prevalence of stroke in India and other countries will increase the demand for stroke rehabilitation services. The present barriers to availability, accessibility and, the lack of awareness about the problem among those affected widen the gap that has to be bridged in order to meet the increasing demand for rehabilitation services. This warrants the development of innovative rehabilitation interventions that can bridge the gap and meet the needs of the affected individual and their families. ‘Care for Stroke’ is one such strategy for addressing the unmet needs for stroke rehabilitation and for bridging the gaps to access to stroke services worldwide.

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Appendix 1

Search Strategy for the systematic review on the incidence and prevalence of stroke in India

Mesh Terms for the Epidemiological Review of Stroke in India

We searched Medline, Embase and Indmed from January 1990 to June 2014 with the following mesh terms

1. “stroke”,
2. “isch(a)emic stroke”,
3. “intracerebral”,
4. “intraparenchymal”,
5. “subarachnoid”,
6. “h(a)emorrhage”,
7. “population-based”,
8. “community-based”,
9. “community”,
10. “epidemiology”,
11. “epidemiological”,
12. “incidence”,
13. “attack rates”,
14. “survey”,
15. “surveillance”,
16. “mortality”,
17. “morbidity”,
18. “fatality”,
19. “case fatality”,
20. “trends”

Appendix 2

Search Strategy for the systematic review of educational interventions for reducing disability following acquired brain injury

Medline Search Strategy

MEDLINE

1. exp Patient Care Team/
2. exp *Rehabilitation/
3. exp *Rehabilitation Nursing/
4. exp *Rehabilitation Centers/
5. exp *Occupational Therapy/
6. exp *Rehabilitation, Vocational/
7. exp *"Activities of Daily Living"/
8. exp *"Quality of Life"/
9. ((activit* adj3 daily living) or ADL or EADL).ab,ti.
10. (rehabilit* or recover* or restor*).ab,ti.
11. exp Disability Evaluation/
12. (disabled or disabil*).ab,ti.
13. (functional adj3 (independ* or capacit*)).ab,ti.
14. exp Disabled Persons/
15. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14
16. exp Education/
17. exp Health Education/
18. exp Patient Education as Topic/
19. exp Self Care/
20. (train* or instruct* or educat* or aware* or teach* or inform* or health?promot*).ti.
21. 16 or 17 or 18 or 19 or 20
22. exp Family/

23. (train* or instruct* or educat* or aware* or teach* or inform* or health?promot*).ti,ab.
24. 21 or 23
25. 22 and 24
26. 21 or 25
27. 15 and 26
28. exp Craniocerebral Trauma/
29. exp Brain Edema/
30. exp Glasgow Coma Scale/
31. exp Glasgow Outcome Scale/
32. exp Unconsciousness/
33. exp Cerebrovascular Trauma/
34. exp Pneumocephalus/
35. exp Epilepsy, post traumatic/
36. ((head or crani* or cerebr* or capitis or brain* or forebrain* or skull* or hemispher* or intra?cran* or inter?cran* or intracran* or intercran*) adj3 (injur* or trauma* or damag* or lesion* or wound* or destruction* or oedema* or edema* or contusion* or concus* or fracture*)).ab,ti.
37. ((head or crani* or cerebr* or brain* or intra?cran* or inter?cran* or intracran* or intercran*) adj3 (haematoma* or hematoma* or haemorrhag* or hemorrhag* or bleed* or pressur*)).ti,ab.
38. (Glasgow adj (coma or outcome) adj (scale* or score*)).ab,ti.
39. "rancho los amigos scale".ti,ab.
40. ("diffuse axonal injury" or "diffuse axonal injuries").ti,ab.
41. ((brain or cerebral or intracranial) adj3 (oedema or edema or swell*)).ab,ti.
42. ((unconscious* or coma* or concuss* or 'persistent vegetative state') adj3 (injur* or trauma* or damag* or wound* or fracture* or contusion* or haematoma* or hematoma* or haemorrhag* or hemorrhag* or pressur*)).ti,ab.
43. exp Cerebral Hemorrhage/
44. exp coma/

45. (injur* or trauma* or damag* or wound* or fractur* or contusion* or haematoma* or hematoma* or haemorrhag* or hemorrhag* or pressur* or lesion* or destruction* or oedema* or edema* or contusion* or concus*).ti,ab.

46. 44 and 45

47. (or/28-43) or 46

48. 27 and 47

49. exp Randomized Controlled Trial/

50. exp controlled clinical trial/

51. exp controlled study/

52. randomi?ed.ab,ti.

53. placebo.ab.

54. *Clinical Trial/

55. exp major clinical study/

56. randomly.ab.

57. (trial or study).ti.

58. 49 or 50 or 51 or 52 or 53 or 54 or 55 or 56 or 57

59. exp animal/ not (exp human/ and exp animal/)

60. 58 not 59

61. 48 and 60

Appendix 3

Study Tools
Phase – 1
Development of the Intervention

**Questionnaire Schedules for the survey conducted
during the rehabilitation needs assessment study**

Study Title: Development of a Smartphone-enabled carer-supported educational intervention for management of disabilities following stroke in India

Study Phase - 1

Questionnaire Schedule for Individuals with Stroke

Participant Study ID:

Date of Interview:

Demographic Details of the Stroke Survivor

Name:

Age:

Gender: Male / Female

Education: No Education; Primary School; Secondary School; Diploma; Degree; Post Graduate; Professional Course

Occupation prior to stroke: Daily wage labor; Class IV Govt/Pvt; Class III/II Govt/Pvt; Class I (Govt) /Pvt; Petty Business; Housework; Not working

Current occupation if any: Daily wage labor; Class IV Govt/Pvt; Class III/II Govt/Pvt; Class I (Govt) /Pvt; Petty Business; Housework; Not working

Annual Family income:

Address and contact details: _____

Caregiver Information:

S.No	Name	Age	Gender	Education	Occupation	Relationship to the stroke survivor	Activities for which support is provided, while caregiving	Approximate time spent in caregiving per day

Clinical Details of the Stroke Survivor

Hospital number:	CT Diagnosis:	Stroke Type: Ischaemic / Haemorrhagic
Date of Hospital admission:	Date of Hospital discharge:	Time since first stroke (in months):
NIH Stroke scale score:	Stroke Severity: Mild / Moderate / Severe	Side Affected: Right / Left Hand
Dominance: Right / Left	Previous stroke if any: Yes / No	If yes when? (Month/year):
Functional status prior to stroke: Completely Independent / Partially Independent / Completely Dependent		
Use of any rehabilitation Aids/Appliances:		

Information provided to participants on responding to the survey questions:

We would appreciate your efforts to answer the following questions to the best of your ability. For each statement please rate the current need by verbally indicating the amount of need for each item with the options mentioned below.

"Not a need"

"Need is already met"

"A small need"

"A moderate need"

"A large need"

"A very large need"

"Not applicable"

"Currently perform this activity with assistance from others"

Determination of Rehabilitation Needs in Individuals Following Stroke

A: Needs related to information about stroke and stroke services

S.No	I need	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	To be aware of the warning signs of recurrent stroke								
2	Information about stroke and its consequences								
3	Information on management of stroke disability								
4	Information on self-management of stroke disability								
5	Information on available rehabilitation services								
6	Information about places where assistive devices & orthotics for stroke are available								
7	Information on disability allowances								
8	Information for their caregiver/family regarding caring for a stroke patient								

B: Needs related to physical symptoms of stroke

S.No	I need	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	Relief from pain								
2	Advice on how to cope with my vision problems								
3	To improve the ability to use my hand(s)								
4	To improve your ability to carry things								
5	To be stronger in my arm(s)								
6	To be stronger in my leg(s)								
7	To be more steady on your feet								
8	To reduce the muscle tightness or spasticity in my arms or legs								
9	To feel less fatigue								
10	To feel less dizzy								
11	To sleep better at night								

C: Needs related to the feelings, memory and emotions of the stroke survivor

S.No	I need	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	To feel less anxious or fearful								
2	To feel less confused								
3	To reduce my forgetfulness								
4	To be better able to control my emotions (tearfulness)								
5	To be less irritable or angry								
6	To stop feeling that I am a burden on my family								
7	To feel less guilty								
8	To feel less lonely								
9	To feel less bored								
10	To worry less about my health								
11	To worry less about money								
12	To feel less self-conscious about my appearance								
13	To feel less depressed								
14	To speak to a trained counsellor about my feelings								

D: Needs related to the stroke survivor's ability to transfer and/or move from place to place

S.No	I need	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	To be better able to move around in bed								
2	To be better able to get in and out of bed or chairs								
3	To be better able to get in and out of bathroom and toilet								
4	To be better able to get on and off of the toilet seat								
5	To be better able to pick up things off the floor								
6	To learn how to get down and up from the floor								
7	To be better able to stand for long periods time								
8	To be better able to walk within home (indoors)								
9	To be better able to walk outdoors								
10	To be better able to walk in crowded places (market)								
11	To be better able to walk up and down stairs								
12	To be better able to use my wheelchair								
13	To be better able to get in and out of public transport (bus/train)								
14	To be better able to get in and out of a car /auto rickshaw								

E: Needs related to the stroke survivor's ability to take care of self

S.No	I need	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	To be better able to brush my teeth								
2	To be better able to feed myself								
3	To be better able to chew and swallow food								
4	To control your saliva (drooling)								
5	To improve your ability to wash and bath myself								
6	To be better able to groom myself								
7	To be better able to dress my lower body								
8	To be better able to dress my upper body								
9	To improve control of my bladder								
10	To improve control of my bowels								

F: Needs related to taking care of home and home affairs

S.No	I need	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	To be able to clean my home								
2	To be able to cook meals								
3	To be able to do laundry								
4	To be able to go shopping								
5	To read my bills, letters and magazines								
6	To be able to use the telephone /mobile phone better								
7	To be able to do my banking								
8	To be able to manage my finances								
9	To be able to care for my family member								

G: Needs related to interacting and communicating with family, friends and others

S.No	I need	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	To improve my ability to speak								
2	To be better able to have a conversation with friends/family								
3	To be better able to make my needs known								
4	To be better able to communicate in an emergency								
5	To be better able to communicate for my banking and shopping								
6	To better understand when people speak to me								
7	To meet people and develop friendships								
8	To be better able to visit places with family								
9	To be better able to show affection								

H: Needs related to Work / Employment

S.No	I need	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	Expert help to find a new job that suits my abilities								
2	To have my job modified to suit my abilities								
3	To be better able to perform my job								
4	Accessible transportation to and from my job								
5	An opportunity to return to work gradually (e.g. part time)								
6	More flexible work schedule to meet my needs								
7	To be better able to communicate in my work								

I: Needs related to social and recreational activities

S.No	I need	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	To be better able to do my hobbies								
2	To be able to attend religious services or events								
3	To be better able to participate in religious traditions in my home								
4	To be able to read better								
5	To participate in sports activities better								
6	To be able to get into buildings such as restaurants, theatres, arenas, religious buildings								
7	More convenient transportation to social activities								
8	More accessible transportation for long distance travel – e.g. Special services for travelling by bus or train								
9	To have more convenient public washroom facilities								

J: Needs related to rehabilitation and medical services

S.No	I need	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	To see my therapist/ more frequently								
2	My therapist to make home visits								
3	To have speech therapy regarding swallowing								
4	To have speech therapy for communication								
5	To have occupational therapy								
6	To have physiotherapy								
7	To have diet/nutritional advice								
8	To have social worker advice								
9	To have nursing support								
10	Therapy that is closer to my home								
11	Improved communication between my therapists and medical professionals								

K: Needs related to other supports in the community

S.No	I need	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	To hear experiences of other people who have had a stroke								
2	To discuss my situation and concerns with other people who have had a stroke								
3	Expert advice on managing disability following stroke								
4	Expert advice on how to make your home accessible								
5	Expert advice on what foods you should be eating								
6	Expert advice on if and how you can safely drive again								
7	A place to exercise that has staff and equipment suitable for people after stroke								

L: Needs related to financial assistance or concessions from government

S.No	I need	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	Concession from government to obtain rehabilitation services from nearby private hospitals								
2	Concessions from government to travel in public transport								
3	Financial support to purchase appliances for your daily living like incontinence pads, walker, walking stick etc.								
4	Someone to help access financial support I may be entitled to (e.g. disability benefits)								

What are your most important needs in relation to rehabilitation? Can you list?

1.

2.

3.

Are these needs met?

If not, what are the major barriers preventing you from meeting your rehabilitation needs?

Who has helped you the most to fulfil your goals or meet your rehabilitation needs and how?

Please give suggestions on what would allow you to meet these rehabilitation needs?

Any other Information

Thank you very much for completing this questionnaire. Your time and effort is much appreciated.

Study Title: Development of a Smartphone-enabled carer-supported educational intervention for management of disabilities following stroke in India

Study Phase - 1

Questionnaire Schedule for Primary Caregivers of Stroke Survivors

Participant Study ID:

Date of Interview:

Demographic Details of the Primary Caregiver of Stroke Survivor

Name:

Age:

Gender: Male / Female

Education: No Education; Primary School; Secondary School; Diploma; Degree; Post Graduate; Professional Course

Relationship to the stroke survivor:

Current occupation if any: Daily wage labor; Class IV Govt/Pvt; Class III/II Govt/Pvt; Class me (Govt) /Pvt; Petty Business; Housework; Not working

Monthly income:

Annual Family income:

Address and contact details: _____

Information about other Caregivers if any:

S.No	Name	Age	Gender	Education	Occupation	Activities Supported	Approximate time spent in caregiving in a day	Relationship to the Stroke survivor

Information provided to participants on responding to the survey questions:

We would appreciate your efforts to answer the following questions to the best of your ability. For each statement please rate the current need by verbally indicating the amount of need for each item with the options mentioned below.

"Not a need"

"Need is already met"

"A small need"

"A moderate need"

"A large need"

"A very large need"

"Not applicable"

"Currently perform this activity with assistance from others"

Determination of Rehabilitation Needs in Individuals Following Stroke

A: Needs related to information about stroke and stroke services

S.No	The stroke survivor you care for needs	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	To be aware of the warning signs of recurrent stroke								
2	Information about stroke and its consequences								
3	Information on management of stroke disability								
4	Information on self-management of stroke disability								
5	Information on available rehabilitation services								
6	Information about places where assistive devices & orthotics for stroke are available								
7	Information on disability allowances								
8	Information for their caregiver/family regarding caring for a stroke patient								

B: Needs related to physical symptoms of stroke

S.No	The stroke survivor you care for needs	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	Relief from pain								
2	Advice on how to cope with their vision problems								
3	To improve the ability to use their hand(s)								
4	To improve their ability to carry things								
5	To be stronger in their arm(s)								
6	To be stronger in their leg(s)								
7	To be more steady on their feet								
8	To reduce the muscle tightness or spasticity in their arms or legs								
9	To feel less fatigue								
10	To feel less dizzy								
11	To sleep better at night								

C: Needs related to the feelings, memory and emotions of the stroke survivor

S.No	The stroke survivor you care for needs	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	To feel less anxious or fearful								
2	To feel less confused								
3	To reduce their forgetfulness								
4	To be better able to control their emotions (tearfulness)								
5	To be less irritable or angry								
6	To stop feeling that they are a burden on to their family								
7	To feel less guilty								
8	To feel less lonely								
9	To feel less bored								
10	To worry less about their health								
11	To worry less about money								
12	To feel less self-conscious about their appearance								
13	To feel less depressed								
14	To speak to a trained counsellor about their feelings								

D: Needs related to the stroke survivor's ability to transfer and/or move from place to place

S.No	The stroke survivor you care for needs	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	To be better able to move around in bed								
2	To be better able to get in and out of bed or chairs								
3	To be better able to get in and out of bathroom and toilet								
4	To be better able to get on and off of the toilet seat								
5	To be better able to pick up things off the floor								
6	To learn how to get down and up from the floor								
7	To be better able to stand for long periods time								
8	To be better able to walk within home (indoors)								
9	To be better able to walk outdoors								
10	To be better able to walk in crowded places (market)								
11	To be better able to walk up and down stairs								
12	To be better able to use their wheelchair								
13	To be better able to get in and out of public transport (bus/train)								
14	To be better able to get in and out of a car /auto rickshaw								

E: Needs related to the stroke survivor's ability to take care of self

S.No	The stroke survivor you care for needs	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	To be better able to brush their teeth								
2	To be better able to feed themselves								
3	To be better able to chew and swallow food								
4	To control their saliva (drooling)								
5	To improve your ability to wash and bath themselves								
6	To be better able to groom themselves								
7	To be better able to dress their lower body								
8	To be better able to dress their upper body								
9	To improve control of their bladder								
10	To improve control of their bowels								

F: Needs related to taking care of home and home affairs

S.No	The stroke survivor you care for needs	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	To be able to clean their home								
2	To be able to cook meals								
3	To be able to do laundry								
4	To be able to go shopping								
5	To read their bills, letters and magazines								
6	To be able to use the telephone /mobile phone better								
7	To be able to do their banking								
8	To be able to manage their finances								
9	To be able to care for their family member								

G: Needs related to interacting and communicating with family, friends and others

S.No	The stroke survivor you care for needs	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	To improve their ability to speak								
2	To be better able to have a conversation with friends/family								
3	To be better able to make their needs known								
4	To be better able to communicate in an emergency								
5	To be better able to communicate for their banking and shopping								
6	To better understand when people speak to them								
7	To meet people and develop friendships								
8	To be better able to visit places with family								
9	To be better able to show affection								

H: Needs related to Work / Employment

S.No	The stroke survivor you care for needs	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	Expert help to find a new job that suits their abilities								
2	To have my job modified to suit their abilities								
3	To be better able to perform their job								
4	Accessible transportation to and from their job								
5	An opportunity to return to work gradually (e.g. part time)								
6	More flexible work schedule to meet their needs								
7	To be better able to communicate in their work								

I: Needs related to social and recreational activities

S.No	The stroke survivor you care for needs	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	To be better able to do their hobbies								
2	To be able to attend religious services or events								
3	To be better able to participate in religious traditions in their home								
4	To be able to read better								
5	To participate in sports activities better								
6	To be able to get into buildings such as restaurants, theatres, arenas, religious buildings								
7	More convenient transportation to social activities								
8	More accessible transportation for long distance travel – e.g. Special services for travelling by bus or train								
9	To have more convenient public washroom facilities								

J: Needs related to rehabilitation and medical services

S.No	The stroke survivor you care for needs	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	To see their therapist/ more frequently								
2	Their therapist to make home visits								
3	To have speech therapy regarding swallowing								
4	To have speech therapy for communication								
5	To have occupational therapy								
6	To have physiotherapy								
7	To have diet/nutritional advice								
8	To have social worker advice								
9	To have nursing support								
10	Therapy that is closer to their home								
11	Improved communication between their therapists and medical professionals								

K: Needs related to other supports in the community

S.No	The stroke survivor you care for needs	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	To hear experiences of other people who have had a stroke								
2	To discuss their situation and concerns with other people who have had a stroke								
3	Expert advice on managing disability following stroke								
4	Expert advice on how to make their home accessible								
5	Expert advice on what foods they should be eating								
6	Expert advice on if and how they can safely drive again								
7	A place to exercise that has staff and equipment suitable for people after stroke								

L: Needs related to financial assistance or government assistance

S.No	The stroke survivor you care for needs	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	Concession from government to obtain rehabilitation services from nearby private hospitals								
2	Concessions from government to travel in public transport								
3	Financial support to purchase appliances for their daily living like incontinence pads, walker, walking stick etc.								
4	Someone to help access financial support they may be entitled to (e.g. disability benefits)								

M: Information Needs of the Primary Caregivers of Stroke Patients

S.No	As a primary caregiver of the stroke survivor, I need	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	Information regarding stroke and its consequences								
2	Information on managing disability following stroke								
3	Information about caring for a stroke patient								
4	Information on available stroke rehabilitation services								

N: Support Needs of the Primary Caregivers of Stroke Patients

S.No	As a primary caregiver of the stroke survivor, I need	Not a need	Need is already met	A small need	Moderate Need	A large need	A very large need	Not Applicable N/A	Currently perform this activity with assistance from others
1	Training to care for a stroke patient								
2	To have professional (therapists) support to care for a stroke patient								
3	Expert advice on managing myself while caring for a stroke patient								
4	To hear experiences of other stroke patient caregivers								
5	To discuss my situation and concerns with other stroke patient caregivers								
6	To speak to a trained counsellor about my feelings								
7	Participate in my usual social and recreational activities								

What are your most important rehabilitation needs of the stroke survivor whom you care for? Can you list?

1. _____

2. _____

3. _____

Are these needs met?

If not, what are the major barriers preventing the stroke survivor whom you care, from meeting these rehabilitation needs?

Please give suggestions on what would allow them to meet these rehabilitation needs?

Please give suggestions on what would allow you to meet the rehabilitation needs of the stroke survivor you care for?

Any other Information

Thank you very much for completing this questionnaire. Your time and effort is much appreciated.

**Topic Guides for the In-depth Interviews conducted
during the rehabilitation needs assessment study**

Objective:

The purpose of this interview is to understand the experience of the stroke survivors in accessing stroke rehabilitation services and their rehabilitation needs. I will use topic guides for conducting in-depth interviews with the stroke survivors and their primary caregivers. This topic guide is to gather more detailed and specific responses around the experiences of access to stroke rehabilitation services and rehabilitation needs that are salient to the stroke survivors.

1. **Introductions and informal conversation**
2. **Go through information sheet:**
 - Reminder of purpose of research
 - Respondent's rights as interviewee regarding the withdrawal from the interview
 - Confidentiality and use of data
3. **Go through written consent form procedures**
 - Gain consent for an audio-recorded interview

Questions to cover

Topics

- Background – General
- Stroke (illness) history
- Management of stroke
- Information needs
- Rehabilitation needs
- Barriers and facilitators to accessing stroke rehabilitation services
- Use of a Smartphone-enabled, carer-supported education program for domiciliary stroke rehabilitation

Background - General

Starter question: Could you please tell me a little bit about yourself...?

Probe:

- Personal information: about the interviewee
 - Education
 - Employment
 - Family
 - Friends
 - Hobbies and interest

Stroke (illness) history

- What happened to you when you had a stroke?

Probe

- Stroke (illness) history
- Identification of warning signs and symptoms of stroke

Management of stroke

- How did you manage your stroke?

Probe

- Accessing emergency and hospital services
- Treatment history
- Access to stroke rehabilitation services
- Current Health Status / Disability

- Current situation in terms of care and support (family / therapy)

Information needs of the stroke survivor

- What information do you still require / need to know in order to manage your disability following stroke?

Probe

- General understanding about stroke related disability and its management
- Knowledge about the sources of information on stroke related disability and its management
- Experience of receiving information about stroke and its management
- Current information needs in terms of stroke related disabilities and its management

Rehabilitation needs of the stroke survivor

- Do you still require any rehabilitation/therapy services to overcome your current disabilities following stroke?

Probe

- Current difficulties (physical, mental, social, personal-care, employment, leisure)
- Knowledge about stroke rehabilitation and its benefits
- Experience of receiving stroke rehabilitation services
- Current rehabilitation/therapy needs in terms of management of stroke related disabilities

Barriers and facilitators to stroke rehabilitation

- What are the major barriers preventing you from meeting your information and rehabilitation needs?

Probe:

- Personal Factors
- Environmental Factors
- Social factors
- Since your stroke, what has helped you the most, to full fill your goals or meet your needs?
- Please give suggestions on what would allow you to meet these needs.

Use of a Smartphone-enabled, carer-supported education program for domiciliary stroke rehabilitation

- Will a Smartphone-enabled, carer-supported education program for domiciliary stroke rehabilitation be useful/helpful to stroke survivors like you?

Probe:

- Abilities and resources required by the stroke survivor to use such intervention
- Advantages and Disadvantages of such intervention

End

- Is there anything you would like to say that you consider to be important?
About your needs, barriers and facilitators
- Do you have any questions?

To Follow-up:

- Rearrange a further interview (if topic guide is not completed in the first interview)
- Ask them who must I also interview to get a good understanding of this issue and what should I ask them?
- Remind them about
 - What will happen to the data (transcript and thesis)
 - Their rights to access the transcript at any time and their rights to knock out any details that they do not like
 - That they can contact me for any further information
 - Dissemination workshop

Objective:

The purpose of this interview is to understand the experience of the stroke survivors in accessing stroke rehabilitation services and their rehabilitation needs. I will use topic guides for conducting in-depth interviews with the stroke survivors and their primary caregivers. This topic guide is to gather more detailed and specific responses around the experiences of access to stroke rehabilitation services and rehabilitation needs that are salient to the stroke survivors.

1. **Introductions and informal conversation**
2. **Go through information sheet:**
 - Reminder of purpose of research
 - Respondent's rights as interviewee regarding the withdrawal from the interview
 - Confidentiality and use of data
3. **Go through written consent form procedures**
 - Gain consent for an audio-recorded interview

Questions to cover

Topics

- Background – General
- Looking after a stroke survivor (history of their care-giving)
- Information needs of the caregiver
- Barriers and facilitators to provision of care
- Use of a Smartphone-enabled, carer-supported education program for domiciliary stroke rehabilitation

Background - General

Starter question: Could you please tell me a little bit about yourself...?

Probe:

- Personal information: about the interviewee
 - Education
 - Employment
 - Family
 - Friends
 - Hobbies and interest

Looking after a stroke survivor (history of their care-giving)

- What happened to the person you care for, when they had a stroke?

Probe

- Stroke (illness) history
- Identification of warning signs and symptoms of stroke

- As a caregiver, what are the ways in which you look after the stroke survivor?

Probe

- Support given to the stroke survivor (Personal-care, Home management, Family support)
- Duration and time spent in care giving

Information needs of the caregivers

- What information do you still require / need to know in order to provide adequate care for the stroke survivor?

Probe

- General understanding about stroke related disability and its management
- Knowledge about the sources of information on stroke related disability and its management
- Experience of receiving information about stroke, its management and care giving
- Current information needs in terms of providing adequate care for the stroke survivor

Barriers and Facilitators to provision of care

- What are the various rehabilitation/therapy needs of the stroke survivor to overcome his/her disabilities following stroke?
- What are the major barriers that prevent you from meeting the needs of the stroke survivor?

Probe:

- Personal Factors
- Environmental Factors
- Social factors
- What has helped you the most, to full fill your goals or meet the needs of the stroke survivor?
- Please give suggestions on what would allow you or another caregiver to meet these needs.

Use of a Smartphone-enabled, carer-supported education program for domiciliary stroke rehabilitation

- Will a Smartphone-enabled, carer-supported education program for domiciliary stroke rehabilitation be useful/helpful to the stroke survivor?

Probe:

- Abilities and resources required by the stroke survivor to use such intervention
- Abilities and resources required by the caregivers to support the stroke survivor to use such intervention
- Advantages and Disadvantages of such intervention

End

- Is there anything you would like to say that you consider to be important?
About needs of the caregiver and the ways to overcome the barriers
- Do you have any questions?

To Follow-up:

- Rearrange a further interview (if topic guide is not completed in the first interview)
- Ask them who must I also interview to get a good understanding of this issue and what should I ask them?
- Remind them about
 - What will happen to the data (transcript and thesis)
 - Their rights to access the transcript at any time and their rights to knock out any details that they do not like
 - That they can contact me for any further information

Objective:

The purpose of this interview is to understand about stroke rehabilitation services provided by the health professionals as well as the barriers and facilitators to provision of stroke rehabilitation services to stroke survivors following hospital discharge. I will use this topic guide for conducting the in-depth interviews with the health professionals providing stroke rehabilitation.

4. Introductions and informal conversation

5. Go through information sheet:

- Reminder of purpose of research
- Respondent's rights as interviewee regarding the withdrawal from the interview
- Confidentiality and use of data

6. Go through written consent form procedures

- Gain consent for an audio-recorded interview

Questions to cover

Topics

- Background – General
- Provision of stroke rehabilitation services to stroke survivors
- Barriers and facilitators to provision of stroke rehabilitation services
- Suggestions to overcome the barriers
- Use of a Smartphone-enabled, carer-supported education program for domiciliary stroke rehabilitation

Background - General

Starter question: Could you please tell me a little bit about yourself...?

Probe:

- About self
- Education
- Professional expertise
- Experience of providing stroke rehabilitation services

Provision of stroke rehabilitation services to stroke survivors

Probe:

- Context for provision of stroke rehabilitation (policies and programs)
- Service statistics at facilities (Admission, treatment and rehabilitation)
- Organization of stroke services (facilities, health professionals, service cost/user fee)
- Service, referral and follow-up pathways
- Support through national programs, policies, civil societies
- Quality of stroke rehabilitation services

Barriers and facilitators to provision of stroke rehabilitation services

Probe:

- Policy
- Resource
- Organization of stroke services
- Pathways for service provision
- Practice standards

Suggestions to overcome the barriers

Probe:

- Policy
- Resource
- Organization of stroke services
- Pathways for service provision
- Practice standards

Use of a Smartphone-enabled, carer-supported education program for domiciliary stroke rehabilitation

- Will a Smartphone-enabled, carer-supported education program for domiciliary stroke rehabilitation be useful/helpful to the stroke survivor?

Probe:

- Abilities and resources required by the stroke survivor to use such intervention
- Abilities and resources required by the caregivers to support the stroke survivor to use such intervention
- Advantages and Disadvantages of such intervention

End

- Is there anything you would like to say that you consider to be important?
About needs of the stroke survivors, caregiver, the ways to overcome the barriers
- Do you have any questions?

To Follow-up:

- Rearrange a further interview (if topic guide is not completed in the first interview)
- Ask them who must I also interview to get a good understanding of this issue and what should I ask them?
- Remind them about
 - What will happen to the data (transcript and thesis)
 - Their rights to access the transcript at any time and their rights to knock out any details that they do not like
 - That they can contact me for any further information

Appendix 4

Study Tools

Phase – 2

Field-testing and finalization of the intervention

Phase – 2: Observation Checklist

Patient (PT) ID:	Caregiver (CG) ID:	Date:
Place:		
Psychiatric problem if any:	Communication problem if any:	Cognitive Problem if any:
NIH Score:	MRS Score:	Barthel Index Score:
Relevance and comprehensibility of the intervention		
Does the stroke survivor have	Yes	No
Needs related to information about stroke?	<input type="checkbox"/>	<input type="checkbox"/>
Needs related to rehabilitation of physical disabilities following stroke?	<input type="checkbox"/>	<input type="checkbox"/>
Needs related to performance of activities of daily living (ADL)?	<input type="checkbox"/>	<input type="checkbox"/>
Needs related to preparing self for daily living?	<input type="checkbox"/>	<input type="checkbox"/>
Needs related to information about assistive devices for his/her disabilities?	<input type="checkbox"/>	<input type="checkbox"/>
Does the primary caregivers of the stroke survivor have		
Needs related to information about stroke?	<input type="checkbox"/>	<input type="checkbox"/>
Needs related to training to care for a stroke survivor?	<input type="checkbox"/>	<input type="checkbox"/>
Needs related to enable the stroke survivor to independently do his/her ADL?	<input type="checkbox"/>	<input type="checkbox"/>
Needs related to enable the stroke survivor to prepare him/herself for ADL?	<input type="checkbox"/>	<input type="checkbox"/>
Can the stroke survivor		
Understand the instruction to operate the smartphone to access the intervention	<input type="checkbox"/>	<input type="checkbox"/>
Access the intervention relevant to his needs?	<input type="checkbox"/>	<input type="checkbox"/>
Read the directions and choices in the application?	<input type="checkbox"/>	<input type="checkbox"/>
View the pictures and access appropriate intervention content?	<input type="checkbox"/>	<input type="checkbox"/>
Operate the symbols/icons in the application to access the intervention?	<input type="checkbox"/>	<input type="checkbox"/>
Slide/scroll the screens for accessing the intervention content?	<input type="checkbox"/>	<input type="checkbox"/>

Can the primary caregivers of the stroke survivor		
Understand the instruction to operate the smartphone to access the intervention	<input type="checkbox"/>	<input type="checkbox"/>
Access the intervention relevant to his needs?	<input type="checkbox"/>	<input type="checkbox"/>
Read the directions and choices in the application?	<input type="checkbox"/>	<input type="checkbox"/>
View the pictures and access appropriate intervention content?	<input type="checkbox"/>	<input type="checkbox"/>
Operate the symbols/icons in the application to access the intervention?	<input type="checkbox"/>	<input type="checkbox"/>
Slide/scroll the screens for accessing the intervention content?	<input type="checkbox"/>	<input type="checkbox"/>
Operational difficulties of the participants in using the smartphone		
Can the stroke survivor	Yes	No
Hold the smartphone with affected hand and operate?	<input type="checkbox"/>	<input type="checkbox"/>
Hold the smartphone with unaffected hand and operate?	<input type="checkbox"/>	<input type="checkbox"/>
Hold the smartphone with both the hands and operate?	<input type="checkbox"/>	<input type="checkbox"/>
Pick up the smartphone and place it on a table top for operating or viewing?	<input type="checkbox"/>	<input type="checkbox"/>
Touch the smartphone screen, as and when required for viewing the visuals?	<input type="checkbox"/>	<input type="checkbox"/>
Slide the smartphone screen, as and when required for viewing the visuals?	<input type="checkbox"/>	<input type="checkbox"/>
View the written information, visuals, icons and videos of the intervention on the smartphone?	<input type="checkbox"/>	<input type="checkbox"/>
Hear the instructions on the videos clearly?	<input type="checkbox"/>	<input type="checkbox"/>
Access the intervention videos without any difficulties?	<input type="checkbox"/>	<input type="checkbox"/>
Can the primary caregiver of the stroke survivor		
Hold the smartphone with their hand and operate?	<input type="checkbox"/>	<input type="checkbox"/>
Hold the smartphone with both the hands and operate?	<input type="checkbox"/>	<input type="checkbox"/>
Pick up the smartphone and place it on a table top for operating or viewing?	<input type="checkbox"/>	<input type="checkbox"/>
Touch the smartphone screen, as and when required for viewing the visuals?	<input type="checkbox"/>	<input type="checkbox"/>
Slide the smartphone screen, as and when required for viewing the visuals?	<input type="checkbox"/>	<input type="checkbox"/>

View the written information, visuals, icons and videos of the intervention on the smartphone?	<input type="checkbox"/>		<input type="checkbox"/>						
Hear the instructions on the videos clearly?	<input type="checkbox"/>		<input type="checkbox"/>						
Access the intervention videos without any difficulties?	<input type="checkbox"/>		<input type="checkbox"/>						
User-friendliness of the intervention									
	Yes		No						
Is the smartphone too big to use?	<input type="checkbox"/>		<input type="checkbox"/>						
Is the Smartphone too heavy to use?	<input type="checkbox"/>		<input type="checkbox"/>						
Is there any difficulty in signing in to access the intervention?	<input type="checkbox"/>		<input type="checkbox"/>						
Is there any difficulty in reading the texts in Tamil or English from the intervention pages?	<input type="checkbox"/>		<input type="checkbox"/>						
Is the size of the texts / words in the intervention pages big enough to read?	<input type="checkbox"/>		<input type="checkbox"/>						
Can the user make out the sections of the intervention from the pictures?	<input type="checkbox"/>		<input type="checkbox"/>						
Are the intervention videos clear and audible?	<input type="checkbox"/>		<input type="checkbox"/>						
Is the size of the Smartphone screen in wide enough to view the intervention videos clearly?	<input type="checkbox"/>		<input type="checkbox"/>						
Can the user view the videos by operating the video icons correctly?	<input type="checkbox"/>		<input type="checkbox"/>						
Can the user view any number of the videos any number of times they need?	<input type="checkbox"/>		<input type="checkbox"/>						
Can the user view any sections of the videos as required by touching/sliding appropriate icons?	<input type="checkbox"/>		<input type="checkbox"/>						
Can the user carry the intervention and view it wherever they go and whenever they need?	<input type="checkbox"/>		<input type="checkbox"/>						
Can the user contact you for any queries through the contact options?	<input type="checkbox"/>		<input type="checkbox"/>						
Technical issues in the Smartphone and Application									
Application issues	Yes	No	Video Issues	Yes	No	Smartphone Issues	Yes	No	Monitoring Issues
Touch option	<input type="checkbox"/>	<input type="checkbox"/>	Video Uploading	<input type="checkbox"/>	<input type="checkbox"/>	Battery life	<input type="checkbox"/>	<input type="checkbox"/>	Report Capture
Slide option	<input type="checkbox"/>	<input type="checkbox"/>	Video streaming	<input type="checkbox"/>	<input type="checkbox"/>	Charging time	<input type="checkbox"/>	<input type="checkbox"/>	Report Generation
Scrolling option	<input type="checkbox"/>	<input type="checkbox"/>	Video viewing	<input type="checkbox"/>	<input type="checkbox"/>	Touch Screen damage	<input type="checkbox"/>	<input type="checkbox"/>	Report Monitoring
Signing in	<input type="checkbox"/>	<input type="checkbox"/>	Media-player default	<input type="checkbox"/>	<input type="checkbox"/>	Heat	<input type="checkbox"/>	<input type="checkbox"/>	
Web page alignment	<input type="checkbox"/>	<input type="checkbox"/>	Picture clarity	<input type="checkbox"/>	<input type="checkbox"/>	Key/Access icon	<input type="checkbox"/>	<input type="checkbox"/>	

						issues			
Thumbnail generation	<input type="checkbox"/>	<input type="checkbox"/>	Sub-Title viewing	<input type="checkbox"/>	<input type="checkbox"/>	Program locking	<input type="checkbox"/>	<input type="checkbox"/>	
Training needs in order to access the intervention from the Smartphone									
						Yes	No		
Training required for stroke survivor?						<input type="checkbox"/>	<input type="checkbox"/>		
Training required for primary Caregiver of stroke survivor?						<input type="checkbox"/>	<input type="checkbox"/>		
Training Manual required?						<input type="checkbox"/>	<input type="checkbox"/>		

Appendix 5

Study Tools

Phase – 3

Pilot-testing the intervention for feasibility and acceptability

Study Title: Development of a Smartphone-enabled carer-supported educational intervention for management of disabilities following stroke in India

Study Phase - 3

Assessment form for Individuals with Stroke

Participant Study ID:

Date of Assessment

Demographic Details of the Stroke Survivor

Name:

Age:

Gender: Male / Female

Education: No Education; Primary School; Secondary School; Diploma; Degree; Post Graduate; Professional Course

Occupation prior to stroke: Daily wage labour; Class IV Govt/Pvt; Class III/II Govt/Pvt; Class I (Govt) /Pvt; Petty Business; Household work; Not working

Current occupation if any: Daily wage labour; Class IV Govt/Pvt; Class III/II Govt/Pvt; Class I (Govt) /Pvt; Petty Business; Household work; Not working

Change in Occupation:

Annual Family income:

Address:

Contact Number

Primary Caregiver:

Secondary Caregiver:

Internet facility at home: Yes/No

Details of Smartphone use:

Experience of using a smartphone prior to stroke: Yes / No

If yes, how long

Does the stroke survivor own a Smartphone: Yes / No

Experience of the Primary caregiver in using a smartphone prior to stroke: Yes / No

If yes, how long

Does the Primary caregiver own a Smartphone: Yes / No

Experience of the Secondary caregiver in using a smartphone prior to stroke: Yes / No

If yes, how long

Does the Secondary caregiver own a Smartphone: Yes / No

Clinical Details of the Stroke Survivor

Hospital number:

CT Diagnosis:

Stroke Type: Ischaemic / Haemorrhagic

Date of Onset:

Admission Date:

Discharge Date:

Time since first stroke (in months):

Previous stroke if any: Yes / No

NIH Stroke scale score:

Stroke Severity: Mild / Moderate / Severe

Side Affected: Right / Left

Upper limb Involvement:

Dominance: Right / Left

Any severe cognitive difficulties: Yes / No

Any severe communication problem: Yes / No

Any Severe co-morbidities (severe psychiatric illness, hearing loss, vision loss): Yes / No

Functional status prior to stroke: Independent / Partially Independent / Dependent

Caregiver Details:

S.No	Name	Age	Gender	Education	Occupation	Relationship to the stroke survivor	Activities for which support is provided, while caregiving	Approximate time spent in caregiving per day

Additional Information if any:

<p>Study Title: Development of a Smartphone-enabled carer-supported educational intervention for management of disabilities following stroke in India</p>
--

Study Phase – 3

Satisfaction Survey

Assessment form for Individual with Stroke

Participant Study ID:

Date of Assessment

Orienting and training participants to the Intervention

1. What was your initial impression about an intervention like this? Please explain
2. When you were told that you would receive this intervention for 4 week, how did you feel?
3. In order to use this intervention, do you think that you need

Training	Support from caregivers	Both	Manage yourself	Not sure
----------	-------------------------	------	-----------------	----------
4. Did you receive sufficient information about the intervention before it was handed over to you?

Yes, definitely	Yes, to some extent	No
-----------------	---------------------	----
5. Were the instructions provided to you to access the intervention from Smartphone clear and understandable?

Yes, definitely	Yes, to some extent	No
-----------------	---------------------	----
6. Do you the think, the demonstration provided to you to access the intervention from Smartphone clear and understandable?

Yes, definitely	Yes, to some extent	No
-----------------	---------------------	----
7. Do you think that the instruction booklet was helpful to you to access the intervention from Smartphone?

Yes, definitely	Yes, to some extent	No
-----------------	---------------------	----
8. Did you get sufficient opportunity to try accessing the intervention from the smartphone yourself - before it was handed over to you?

Yes, definitely	Yes, to some extent	No
-----------------	---------------------	----
9. Did you have enough confidence to try out this intervention when it was provided to you?

Yes, definitely	Yes, to a greater extent,	Yes, to some extent	Yes to a very small extent
Not confident			
10. Overall do you think you received sufficient training and support to access the intervention from the smartphone?

Yes, definitely	Yes, to some extent	No
-----------------	---------------------	----

Accessing the intervention

11. Did you access the intervention videos on the smartphone by yourself? Yes / No

If yes, go to question 12 if no, go to question 14

12. Was it easy to navigate between the webpages and the intervention videos easily?

Yes, definitely Yes, to some extent No

13. Did you have any difficulty in accessing the intervention videos from smartphone? Yes / No

If yes, please mention the difficulties you experienced.

14. Who helped you to watch the intervention videos? _____

15. Was it easy for them to navigate between the webpages and the intervention videos easily?

Yes, definitely Yes, to some extent No

16. Did they have any difficulty in accessing the intervention from smartphone? Yes / No

If yes, please mention the difficulties that they experienced.

Content of the Intervention

17. Do you think that the video information was presented in a way you could watch and understand?

Yes, Definitely Yes, to some extent No

18. Were the intervention videos relevant to your current needs?

Yes, completely Yes, to some extent No

19. Which section was more interesting?

Stroke information	Home-based exercises	Assistive devices	Functional skills	ADL	All
None					

20. Which section was less interesting?

Stroke information	Home-based exercises	Assistive devices	Functional skills	ADL	All
None					

Utilisation of the Intervention

21. How do you feel about the length of time from being discharged from hospital to being given this intervention

The intervention was given to me earlier than I thought was necessary

The intervention was given to me as soon as I thought was necessary

The intervention should have been given to me sooner

The intervention should have been given to me much sooner

22. How often did you watch the intervention videos in the past four weeks?

Once or more than once daily Once or more than once weekly Whenever necessary

Whenever possible Did not use

23. Was it only you, who watched the intervention videos? yes / no

24. If no, please mention those who watched the intervention videos

25. Do you think that the videos were useful to you?

Yes, completely Yes, to some extent No

26. If yes, in what ways were the videos useful to you? Please explain

27. Please mention three things that you liked most about this intervention

28. Please mention three things that you liked least about this intervention

29. Have you seen similar kind of videos before? Yes / No

30. If yes, was there anything new in these videos – please explain?

31. Did you try doing some activities or exercises yourself, after watching from the videos?

Yes, always Yes, frequently Yes, Occasionally, Yes, Rarely, Never practice

32. Do you think, four weeks is sufficient time given to you to use this smartphone intervention?

Yes, definitely yes, probably No, I will need it for some more time

33. Will you use this intervention even after you give the smartphone back? Yes / No

34. If yes, how will you do that? Please explain

35. Overall, Did you like this intervention

Yes, definitely Yes, to a great extent Yes, to some extent No

36. Do you think this intervention would be useful for someone affected by stroke?

Yes, definitely Yes, probably No

37. How useful was this intervention?

Extremely useful Very useful Useful to an extent Not useful

38. How would you rate the smartphone-enabled intervention you received?

Excellent Very good Good Fair Poor

39. Would you recommend this intervention to your friends and family?

Yes, definitely Yes, probably No

40. If no, please comment

41. Other Comments / Suggestions

<p>Study Title: Development of a Smartphone-enabled carer-supported educational intervention for management of disabilities following stroke in India</p>
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Study Phase – 3

Satisfaction Survey

Assessment form for Caregivers of Individual with Stroke

Participant Study ID:

Date of Assessment

Orienting and training participants to the Intervention

1. What was your initial impression about an intervention like this? Please explain
2. When you were told that you would receive this intervention for 4 week, how did you feel?
3. To support the stroke survivor in using this intervention, do you think that you need

Training	Support from caregivers	Both	Manage yourself	Not sure
----------	-------------------------	------	-----------------	----------
4. Did you receive sufficient information about the intervention before it was handed over to you?

Yes, definitely	Yes, to some extent	No
-----------------	---------------------	----
5. Were the instructions provided to you to access the intervention from Smartphone clear and understandable?

Yes, definitely	Yes, to some extent	No
-----------------	---------------------	----
6. Do you the think, the demonstration provided to you to access the intervention from Smartphone clear and understandable?

Yes, definitely	Yes, to some extent	No
-----------------	---------------------	----
7. Do you think that the instruction booklet was helpful to you to access the intervention from Smartphone?

Yes, definitely	Yes, to some extent	No
-----------------	---------------------	----
8. Did you get sufficient opportunity to try accessing the intervention from the smartphone yourself - before it was handed over to you?

Yes, definitely	Yes, to some extent	No
-----------------	---------------------	----
9. Did you have enough confidence to try out this intervention when it was provided to you?

Yes, definitely	Yes, to a greater extent,	Yes, to some extent	Yes to a very small extent
Not confident			
10. Overall do you think you received sufficient training and support to access the intervention from the smartphone?

Yes, definitely	Yes, to some extent	No
-----------------	---------------------	----

Accessing the intervention

11. Did you access the intervention videos on the smartphone by yourself? Yes / No

If yes, go to question 12 if no, go to question 14

12. Was it easy to navigate between the webpages and the intervention videos easily?

Yes, definitely Yes, to some extent No

13. Did you have any difficulty in accessing the intervention videos from smartphone? Yes / No

If yes, please mention the difficulties you experienced.

14. Who helped you to watch the intervention videos? _____

15. Was it easy for them to navigate between the webpages and the intervention videos easily?

Yes, definitely Yes, to some extent No

16. Did they have any difficulty in accessing the intervention from smartphone? Yes / No

If yes, please mention the difficulties that they experienced.

Content of the Intervention

17. Do you think that the video information was presented in a way you could watch and understand?

Yes, Definitely Yes, to some extent No

18. Were the intervention videos relevant to the current needs of the stroke survivor?

Yes, completely Yes, to some extent No

19. Which section was more interesting to the stroke survivor?

Stroke information	Home-based exercises	Assistive devices	Functional skills	ADL	All
None					

20. Which section was more interesting to you?

Stroke information	Home-based exercises	Assistive devices	Functional skills	ADL	All
None					

Utilisation of the Intervention

21. How do you feel about the length of time from being discharged from hospital to being given this intervention

The intervention was given to us earlier than I thought was necessary

The intervention was given to us as soon as I thought was necessary

The intervention should have been given to us sooner

The intervention should have been given to us much sooner

22. How often did the stroke survivor watch the intervention videos in the past four weeks?

Once or more than once daily Once or more than once weekly Whenever necessary

Whenever possible Did not use

23. Was it only the stroke survivor, who watched the intervention videos? yes / no

24. If no, please mention those who watched the intervention videos

25. Do you think that the videos were useful to the stroke survivor?

Yes, completely Yes, to some extent No

26. If yes, in what ways were the videos useful to them? Please explain

27. Please mention three things that you liked most about this intervention

28. Please mention three things that you liked least about this intervention

29. Have you seen similar kind of videos before? Yes / No

30. If yes, was there anything new in these videos – please explain?

31. Did the stroke survivor try doing some activities or exercises themselves or with the help of the family after watching from the videos?

Yes, always Yes, frequently Yes, Occasionally, Yes, Rarely, Never practice

No

32. Do you think, four weeks is sufficient time given to the stroke survivor and you to use this smartphone intervention?

Yes, definitely yes, probably No, I will need it for some more time

33. Will you support the stroke survivor in using this intervention even after you give the smartphone back? Yes / No

34. If yes, how will you do that? Please explain

35. Overall, Did you like this intervention

Yes, definitely Yes, to a great extent Yes, to some extent No

36. Do you think this intervention would be useful for someone affected by stroke?

Yes, definitely Yes, probably No

37. How useful was this intervention?

Extremely useful Very useful Useful to an extent Not useful

38. How would you rate the smartphone-enabled intervention you received?

Excellent Very good Good Fair Poor

39. Would you recommend this intervention to your friends and family?

Yes, definitely Yes, probably No

40. If no, please comment

41. Other Comments / Suggestions

Appendix 6

Informed Consent Forms

Phase – 1

Study title: Development and evaluation of a Smartphone-enabled carer-supported educational intervention for management of disabilities following stroke in India

ஆய்வு தலைப்பு: இந்தியாவில் பக்கவாதம் பாதித்ததை தொடர்ந்து ஏற்படும் செயலிழப்புகளை சமாளிக்க, ஒரு ஸ்மார்ட்போன் துணையுடன், கவனிப்பாளரின் ஆதரவுடன் செயல்படுத்தப்பட்ட கல்விமுறையிலான புனர்வாழ்வு சிகிச்சையின் உருவாக்கம்.

Participant Information Sheet – Phase 1
and 2

பங்கேற்பாளர் தகவல் தாள் - கட்டம் 1 மற்றும் 2

Dear Sir/Madam,
அன்புள்ள ஐயா/அம்மா,

Namaskar, My name is Suresh Kumar and I am a research degree student at the London School of Hygiene and Tropical Medicine (United Kingdom).

வணக்கம், எனது பெயர் சுரேஷ் குமார். லண்டன் ஸ்கூல் ஆஃப் ஹைஜீன் அன்ட் டிராபிக் கல்வி முறையிலான (யுனைட்டெட் கிங்டம்) என்னும் கல்வி நிறுவனத்தில் நான் ஒரு ஆராய்ச்சி பட்டதாரி மாணவராக இருக்கிறேன்.

Purpose of the study:

This study will assist in developing a Smartphone-enabled carer-supported educational intervention for disabilities following stroke that could potentially help meet the rehabilitation needs of stroke survivors and their caregivers. The purpose of this study is to understand the experiences of stroke survivors and their caregivers in accessing stroke services, their needs, barriers and facilitators for stroke rehabilitation services and the roles and needs of people who care for them.

இந்த ஆய்வின் நோக்கம்:

இந்த ஆய்வானது பக்கவாதத்தால் ஏற்படும் செயலிழப்புகளை சமாளிப்பதற்கான ஒரு ஸ்மார்ட்போன் துணையுடன், கவனிப்பாளரின் ஆதரவுடன் செயல்படுத்தப்பட்ட கல்விமுறையிலான புனர்வாழ்வு சிகிச்சை ஒன்றை உருவாக்க துணை புரியும். இந்த ஆய்வு பக்கவாதம் வந்து உயிர் பிழைத்தவர்களின் புனர்வாழ்வு தேவைகளையும் அவர்களை கவனித்து கொள்பவரின் தேவைகளையும் பூர்த்திசெய்ய உதவும் என எதிர்பார்க்கப்படுகிறது. இந்த ஆய்வின் நோக்கமானது பக்கவாதத்தால் பாதிக்கப்பட்டவரின் புனர்வாழ்வு சிகிச்சை அனுபவங்களையும், அவர்களின் புனர்வாழ்வு தேவைகளையும், சிகிச்சை பெறுவதில் உள்ள இடர்பாடுகளையும், அதை சமாளிக்க உள்ள வழிகளையும் மற்றும் பக்கவாதத்தால் பாதிக்கப்பட்டவரை கவனிதிகொள்பவரின் தேவைகளையும், பங்களையும் புரிந்துகொள்வதே ஆகும்.

Questions and Concerns:

You are being invited to participate in this study. Kindly read / listen to this information attentively. If you are not clear about anything or if there is any uncertainty, then you are free to ask any questions to me. Please sign the consent letter only when you are able to understand the nature of this study and your rights as a participant. You are free to discuss it with anybody, whose consultation is important to you.

கேள்விகள் மற்றும் சந்தேகங்கள்:

இந்த ஆய்வில் பங்கேற்பதற்காக நீங்கள் அழைக்கப்பட்டுளீர்கள். அன்புகூர்ந்து இந்த தகவல்களைக் கவனமாகப் படியுங்கள்/கேளுங்கள். உங்களுக்கு ஏதேனும் தெளிவாக விளங்கவில்லை என்றாலும் அல்லது ஏதாவது ஐயமிருந்தாலும், அதைபற்றி என்னிடம் கேட்பதற்கு உங்களுக்கு அனைத்து சுதந்திரமும் உள்ளது. இந்த ஆய்வின்

தன்மை பற்றியும், ஒரு பங்கேற்பாளராக உங்களது உரிமைகள் பற்றியும் உங்களால் புரிந்துகொள்ளமுடிந்தால் மட்டுமே, இந்த சம்மதக் கடிதத்தில் உங்கள் கையொப்பத்தை இடுமாறு உங்களை கேட்டுக்கொள்கிறேன். யாருடனாவது கலந்தாலோசிப்பது முக்கியம் என்று நீங்கள் கருதுகின்ற யாரிடமும், நீங்கள் இது பற்றி விவாதிப்பதற்கு உங்களுக்கு சுதந்திரம் இருக்கிறது.

Voluntary Participation:

It is entirely your decision to participate in this study. If you want to discontinue at any point of time, you are free to do so without stating any reason. Your non- participation will not be held against you in any manner.

தன்னிச்சையான பங்கேற்பு:

இந்த ஆய்வில் பங்கேற்பது என்பது முழுவதுமாக உங்களது முடிவே ஆகும். எந்த நேரத்திலாவது நீங்கள் இந்த ஆய்வில் இருந்து விலக விரும்பினால், காரணம் எதையும் கூறாமல் விலகுவதற்கு உங்களுக்கு முழு சுதந்திரம் உள்ளது. நீங்கள் பங்கேற்காமல் போனால் கூட உங்களுக்கு எதிராக எந்த முறையிலும் எவ்விதமான நடவடிக்கையும் இருக்காது.

What it means to participate?

During this study, we propose to conduct a survey and/or talk to the stroke survivors and their caregivers about their experiences and needs for stroke rehabilitation. This process will take around 60-90 minutes and we would appreciate your efforts to answer the questions to the best of your ability. I will show you a Smartphone-enabled educational intervention (sample for illustration) to facilitate your understanding about the kind of intervention that will be developed from the study. In case you feel uncomfortable during the survey/interview process you can either decide to continue at a later time or not to continue at all. The interviews will be tape recorded and if you do not want me to record, I will take written notes of the interview. If you have any queries regarding the study, you can contact me at any time on the number mentioned below. The information so collected will be kept confidential will be used only for study purposes without disclosing your personal identity.

இந்த ஆய்வில் பங்கேற்பது என்பதன் பொருள் என்ன?

இந்த ஆய்வின் பொழுது பக்கவாதம் வந்து பிழைத்தவர்கள் மற்றும் அவர்களுக்கு கவனிப்பு தருபவர்களிடம் பக்கவாத புனர்வாழ்வின் அனுபவங்கள் மற்றும் தேவைகள் பற்றிய ஒரு சர்வே நடத்துவதற்கும் மற்றும்/அல்லது பேசுவதற்கும் நாங்கள் முன்மொழிகிறோம்: இந்த செயல்முறைக்கு சுமார் 60-90 நிமிடங்கள் பிடிக்கும். இந்த ஆய்வின் கேள்விகளுக்கு உங்களது சிறப்பான திறன் கொண்டு பதிலளிப்பதற்கு நீங்கள் எடுக்கும் முயற்சிகளை நான் பெய்தும் மெச்சுகிறேன். இந்த ஆய்வில் இருந்து உருவாக்கப்படவுள்ள கல்வி ரீதியிலான சிகிச்சையை பற்றி நீங்கள் புரிந்து கொள்வதற்கு வசதியாக ஒரு ஸ்மார்ட்போன் துணையுடன் செய்யப்பட்ட கல்வி ரீதியிலான சிகிச்சையை (விளக்கத்திற்கான மாதிரி) ஒன்றை நான் உங்களுக்கு காண்பிப்பேன். இந்த சர்வேயின்/நேர்காணல்களின் செயல்முறையின் பொழுது நீங்கள் ஒருவேளை அசௌகரியமாக உணர்ந்தால் நீங்கள் பின்னொரு சமயத்தில் அதைத் தொடர்ந்திட முடிவு செய்யலாம் அல்லது தொடராமலே விட்டு விடலாம். இந்த நேர்காணல்கள் பதிவு செய்யப்படும். நேர்காணலை நான் பதிவு செய்வதை நீங்கள் விரும்பாவிட்டால் அந்த நேர்காணலின் போது, நான் குறிப்புகளை மட்டும் எடுத்துக்கொள்வேன். ஆய்வு பற்றிய கேள்விகள் எதுவும் உங்களுக்கு இருந்தால் கீழே குறிப்பிட்ட எண்ணில் எந்த நேரமும் நீங்கள் என்னைத் தொடர்பு கொண்டு கேட்கலாம். இவ்வாறு சேகரிக்கப்பட்ட தகவல்கள் ரகசியமாக வைக்கப்படும் மற்றும் ஆய்வு நோக்கங்களுக்காக மட்டுமே அவை உங்களது தனிப்பட்ட அடையாளத்தை வெளிப்படுத்தாமல் பயன்படுத்தப்படும்.

Future studies:

Based on the findings from the present study, I would conduct further studies. Thus I would like to invite you to continue to participate in the future, if you wish.

எதிர்கால ஆய்வுகள்:

இந்த தற்பொழுதைய ஆய்வில் கண்டுபிடித்தவைகளின் அடிப்படையில் கூடுதல் ஆய்வுகளை நான் நடத்துவேன். இதில் நீங்கள் கலந்துகொள்ள விரும்பினால் எதிர் காலத்தில் தொடர்ந்து பங்கேற்பதற்கு நான் உங்களை வரவேற்கிறேன்.

Risk of participating in the study:

I do not expect that you will incur any risks by participating in the study.

இந்த ஆய்வில் பங்கேற்பதன் அபாயம்:

இந்த ஆய்வில் பங்கேற்பதால் உங்களுக்கு எந்தவித அபாயமும் இருக்காது.

Confidentiality:

If you decide to participate in the study, all details provided by you will be kept confidential and it will be made available to the research investigators related to this study. Information collected from you will be stored securely in a locked cabinet and a password protected computer. The results will be published in research magazines and reports. However the names and personal details of the study participants will not be disclosed and you will not be recognized from them.

ஆய்வின் ரகசியத்தன்மை:

இந்த ஆய்வில் பங்கேற்பதற்கு நீங்கள் முடிவு செய்தால் உங்களால் தரப்படும் அனைத்து விபரங்களும் ரகசியமாக வைக்கப்படும் மற்றும் அவை இந்த ஆய்வு தொடர்பான ஆராய்ச்சி ஆய்வாளர்களுக்கு மட்டுமே கிடைக்கச் செய்யப்படும். உங்களிடமிருந்து சேகரிக்கப்பட்ட தகவல்கள் பூட்டிய பெட்டகம் ஒன்றிலும் கடவுச் சொல் கொண்டு பாதுகாக்கப்பட்ட கணினியிலும் பத்திரமாக சேமித்து வைக்கப்படும். அந்த முடிவுகள் ஆராய்ச்சி பத்திரிகைகள் மற்றும் அறிக்கைகளில் பிரசுரம் செய்யப்படும். இருப்பினும் ஆய்வில் பங்கேற்றவர்களின் பெயர்கள் மற்றும் தனிப்பட்ட விபரங்கள் பிரசுரம் செய்யப்படும் அறிக்கையில் வெளிக்காட்டப்பட மாட்டாது மற்றும் நீங்கள் அவற்றில் இருந்து அடையாளம் காணப்பட மாட்டீர்கள்.

Funding:

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நிதி பெறுதல்:

இந்த ஆய்வுக்கான நிதி வெல்கம் டிரஸ்ட்-பப்ளிக் ஹெல்த் ஃபவுண்டேசன் ஆஃப் இந்தியா என்ற அமைப்பின், கெப்பசிட்டி பில்டிங் ஸ்ட்ரேட்டிக்ஜிக் அவார்ட் மூலம் அளிக்கப்படுகிறது.

Contact for further information:

If you have any questions, please contact Suresh Kumar at the Indian Institute of Public Health, Plot no: 1, ANV Arcade, Amar co-op Society, Kavuri Hills, Madhapur, Hyderabad. Phone: 040-49006021, Mobile: 0091-9840772381.

கூடுதல் தகவல்களுக்கு தொடர்பு கொள்ளுங்கள்:

உங்களிடம் கேள்விகள் ஏதேனும் இருந்தால் இந்தியன் இன்ஸ்டிடியூட் ஆஃப் பப்ளிக் ஹெல்த் இ பிளாட் எண்: 1 ஏஎன்வி (யூ.என்.ஏ) ஆர்க்கேட் அமர் கோ-ஆப் சொசைட்டி காவிரி ஹில்ஸ் மாதாப்பூர் ஹைதராபாத். தொலைபேசி எண்: 040-49006050 மொபைல் எண்: 0091-9840772381 என்னும் முகவரியில் உள்ள சுரேஷ்குமாரை தயவுசெய்து தொடர்பு கொள்ளுங்கள்.

Information Sheet about stroke பக்கவாதம் பற்றிய தகவல் தாள்

What is Stroke?

A stroke occurs when the blood supply to part of the brain is suddenly interrupted or when a blood vessel in the brain bursts, spilling blood into the spaces surrounding brain cells. Brain cells die when they no longer receive oxygen and nutrients from the blood or there is sudden bleeding into or around the brain. The symptoms of a stroke include sudden numbness or weakness, especially on one side of the body; sudden confusion or trouble speaking or understanding speech; sudden trouble seeing in one or both eyes; sudden trouble with walking, dizziness, or loss of balance or coordination; or sudden severe headache with no known cause. There are two forms of stroke: *ischemic* - blockage of a blood vessel supplying the brain, and *haemorrhagic* - bleeding into or around the brain.

பக்கவாதம் என்பது என்ன?

மூளையின் ஒரு பகுதிக்கு இரத்த வினியோகம் திடீரென்று தடைப்படும் பொழுது அல்லது மூளையில் உள்ள ஒரு இரத்த நாளம் வெடித்து சிதறி பாயும் இரத்தமானது மூளையின் செல்களைச் சுற்றிலும் உள்ள இடைவெளிகளுக்குள் பாயும் பொழுது பக்கவாதம் நேர்கிறது. இதனால் மூளை இயங்குவதற்கு தேவையான அக்ஸிஜனும் ஊட்டசத்தும் மூளைக்கு கிடைக்காத பட்சத்தில், மூளையின் செல்கள் இறந்துவிடுகின்றன. பக்கவாதத்தின் அறிகுறிகளாக திடீரென்று உடல் மரத்துப் போவது அல்லது பலவீனமடைவது; குறிப்பாக உடலின் ஒரு பக்கத்தில் அது ஏற்படுவது; திடீர் குழப்பம், பேசுவதில் அல்லது பேச்சைப் புரிந்து கொள்வதில் சிரமம், ஒரு கண்ணால் அல்லது இரண்டு கண்களாலும் பார்ப்பதில் திடீரென்று சிரமம்; நடப்பதில் திடீரென்று சிரமம், கிறுகிறுப்பு, உடலின் சமநிலையை அல்லது ஒருங்கிணைத்தலை இழப்பது; அறியப்படாத காரணத்தால் திடீரென்று தீவிரமான தலைவலி ஏற்படுவது. இவை அனைத்தும் பக்கவாதத்தின் அறிகுறிகளாகும். பக்கவாதத்தில் இரண்டு வகை உண்டு: ஒன்று இஸ்கெமிக் - மூளைக்கு இரத்தம் வினியோகிக்கும் நாளம் ஒன்றில் அடைப்பு ஏற்படுவது மற்றொன்று ஹெமரஜிக் - மூளையினுள் அல்லது மூளையைச் சுற்றிலும் இரத்தக்கசிவு ஏற்படுவது.

Is there any treatment?

Generally there are three treatment stages for stroke: prevention, therapy immediately after the stroke, and post-stroke rehabilitation. Therapies to prevent a first or recurrent stroke are based on treating an individual's underlying risk factors for stroke, such as hypertension, atrial fibrillation, and diabetes. Acute stroke therapies try to stop a stroke while it is happening by quickly dissolving the blood clot causing an ischemic stroke or by stopping the bleeding of a haemorrhagic stroke. Post-stroke rehabilitation helps individuals overcome disabilities that result from stroke damage. Medication or drug therapy is the most common treatment for stroke. The most popular classes of drugs used to prevent or treat stroke are antithrombotic (anti-platelet agents and anticoagulants) and thrombolytic.

இதற்கு சிகிச்சை எதுவும் இருக்கிறதா?

பொதுவாக பக்கவாதத்தில் மூன்று சிகிச்சை கட்டங்கள் உள்ளன: பக்கவாதம் வராமல் தடுப்பது, பக்கவாதம் நேர்ந்த உடனே சிகிச்சை அளிப்பது மற்றும் பக்கவாதத்திற்குப் பிந்தைய மறுவாழ்வு சிகிச்சை. முதல்முறை அல்லது அடுத்தடுத்து நேரும் பக்கவாதத்தைத் தடுப்பதற்கான சிகிச்சைகள், பக்கவாதம் நேர்வதற்கு அடிப்படையாக இருக்கும் அபாயக் காரணிகளான, மிக அதிகமான இரத்த அழுத்தம், இதயம் சீரற்று துடிப்பது (ஏட்ரியல் ஃபைப்ரில்லேசன்) மற்றும் நீரிழிவு நோய் போன்றவற்றை குணப்படுத்துவதையே அடிப்படையாக கொண்டுள்ளது. பக்கவாதம் வந்த சில மணிநேரத்திலேயே கொடுக்கப்படும் தீவிர சிகிச்சைகள் பக்கவாதம் ஒன்று நேரும் பொழுது துரிதமாக இரத்தக்கட்டியைக் கரைத்து (இஸ்கெமிக்), பக்கவாதம் ஏற்படுத்துவதைத் தடுத்தும் அல்லது இரத்தக்கசிவைத் தடுப்பதன் (ஹெமரஜிக்) மூலமாகவும் பக்கவாதம் நேர்வதைத் தடுக்க முயற்சிக்கிறது. பக்கவாதத்திற்குப் பிந்தைய மறுவாழ்வு ஆனது பக்கவாத சேதத்தின் விளைவினால் நேரிடும் செயலிழப்புகளை சமாளிப்பதற்கு உதவுகிறது. பக்கவாதத்திற்கு மிகப் பொதுவான சிகிச்சை மருந்து அளிப்பதே ஆகும். பக்கவாதத்தைத் தடுப்பதற்கு அல்லது சிகிச்சைக்குப் பயன்படும் மிகவும் பிரபலமான மருந்துகளின் வகுப்புகள் ஆன்ட்டித்ராம்போட்டிக், ஆன்ட்டி-பிளேட்லெட்

ஏஜென்டுகள் மற்றும் ஆன்ட்டிகோயாகுலன்டுகள் மற்றும் த்ராம்போலைட்டிக் ஆகியவை ஆகும்.

What is the prognosis?

Although stroke is a disease of the brain, it can affect the entire body. A common disability that results from stroke is complete paralysis on one side of the body, called *hemiplegia*. A related disability that is not as debilitating as paralysis is one-sided weakness or *hemiparesis*. Stroke may cause problems with thinking, awareness, attention, learning, judgment, and memory. Stroke survivors often have problems understanding or forming speech. A stroke can lead to emotional problems. Stroke patients may have difficulty controlling their emotions or may express inappropriate emotions. Many stroke patients experience depression. Stroke survivors may also have numbness or strange sensations. The pain is often worse in the hands and feet and is made worse by movement and temperature changes, especially cold temperatures. Recurrent stroke is frequent; about 25 percent of people who recover from their first stroke will have another stroke within 5 years.

நோய் பற்றிய முன்கணிப்பு

பக்கவாதம் என்பது மூளையின் ஒரு நோய் என்றாலும் கூட அது முழு உடலையும் பாதிக்கக்கூடியது ஆகும். பக்கவாதத்தினால் நேரிடும் ஒரு பொதுவான செயலிழப்பு ஹெமிபிளஜியா என்று அழைக்கப்படும் அது, உடலின் ஒரு பக்கம் ஆனது முழுமையாக முடக்குவாதத்தால் செயலிழந்து போய்விடுவது ஆகும். இது போன்ற உடலின் ஒரு பக்கம் முடக்குவாதத்தால் பாதிக்கபடாமல் பலவீனம் மட்டும் அடைவது ஹெமிபேரசிஸ் என்று அழைக்கப்படும். பக்கவாதம் ஆனது சிந்திப்பதில், விழிப்புணர்வில், கவனத்தில், கற்றுக் கொள்வதில், திறனாய்வு செய்வதில் மற்றும் ஞாபகத்திறன் ஆகியவற்றில் பிரச்சினைகளை ஏற்படுத்தலாம். பக்கவாதம் வந்து பிழைத்தவர்களுக்கு பெரும்பாலும் பேச்சைப் புரிந்து கொள்வதில் அல்லது பேச்சை உருவாக்குவதில் பிரச்சினைகள் நேர்கின்றன. பக்கவாதம் ஆனது உணர்வு ரீதியான பிரச்சினைகளை கூட ஏற்படுத்தலாம். பக்கவாதம் வந்த நோயாளிகளுக்கு தங்களது உணர்வுகளைக் கட்டுப்படுத்துவதில் சிரமம் இருக்கலாம் அல்லது அவர்கள் பொருத்தமற்ற உணர்வுகளை வெளிப்படுத்தலாம். பக்கவாதம் வந்த பல நோயாளிகள் மனஅழுத்தத்தை அனுபவிக்கின்றனர். பக்கவாதம் வந்து பிழைத்தவர்களுக்கு உடல் உணர்வின்மை (உடல் மருதுபோவது) அல்லது வித்தியாசமான உணர்வுகளும் இருக்கலாம். பக்கவாதம் வந்தவருக்கு பொதுவாக, கைகள் மற்றும் பாதங்களில் அடிக்கடி வலி மோசமாக இருக்கும் மற்றும் அந்த வலியானது உடல் அசைவதாலும், வெப்பநிலை மாற்றங்களாலும் குறிப்பாக குளிர்ந்த வெப்பநிலைகளில் மோசமடைகிறது. ஒரு முறை பக்கவாதம் வந்தவருக்கு மறுமுறை பக்கவாதம் வருவதற்கு பெரிதும் வாய்ப்புள்ளது. முதல்முறை பக்கவாதத்தில் இருந்து மீள்பவர்களில் 25 சதவிகிதம் பேருக்கு 5 ஆண்டுகளுக்கு உள்ளாக அடுத்து ஒரு பக்கவாத தாக்குதல் நேரிட வாய்ப்புள்ளது.

Source: National Institute of neurological disorders and stroke

தகவல் மூலம்: நேசனல் இன்ஸ்டிடியூட் ஆஃப் நியூராலஜிக்கல் டிஸார்டர்ஸ் அன்ட் ஸ்ட்ரோக்

Informed Consent form – Phase 1 and 2

தகவல் தெரிவிக்கப்பட்ட சம்மதப் படிவம் - கட்டம் 1 மற்றும் 2

“Development and evaluation of a Smartphone-enabled carer-supported educational intervention for management of disabilities following stroke in India”

“இந்தியாவில் பக்கவாதம் பாதித்ததைத் தொடர்ந்து ஏற்படும் செயலிழப்புகளை சமாளிக்க, ஒரு ஸ்மார்ட்போன் துணையுடன் கவனிப்பாளரின் ஆதரவுடன் செயல்படுத்தப்பட்ட கல்விமுறையிலான புனர்வாழ்வு சிகிச்சையின் உருவாக்கம்”

I give my consent to Suresh Kumar, from the London School of Hygiene and Tropical Medicine (LSHTM) to participate in the study. My participation in this study will help in developing a Smartphone-enabled, carer-supported educational intervention for management of stroke related disabilities that could potentially meet the rehabilitation needs of stroke survivors.

இந்த ஆய்வில் கலந்து கொள்வதற்காக எனது சம்மதத்தை சுரேஷ்குமார் என்னும் லண்டன் ஸ்கூல் ஆஃப் ஹைஜீன் அன்ட் டிராப்பிக்கல் மெடிசின் (எல்எஸ்எச்டிஎம்) (LSHTM) என்னும் கல்வி நிறுவனத்தைச் சேர்ந்தவருக்குத் தருகிறேன். இந்த ஆய்வில் எனது பங்கேற்பானது பக்கவாதம் பாதித்ததைத் தொடர்ந்து ஏற்படும் செயலிழப்புகளை சமாளிக்க, ஒரு ஸ்மார்ட்போன் துணையுடன் கவனிப்பாளரின் ஆதரவுடன் செயல்படுத்தப்பட்ட கல்விமுறையிலான புனர்வாழ்வு சிகிச்சையை உருவாக்குவதற்கு உதவிடும். அது பக்கவாதம் வந்து உயிர் பிழைத்தவர்களின் புனர்வாழ்வு தேவைகளை பூர்த்திசெய்ய உதவிடும்.

I am aware if I have any further enquiries about the interview, I can contact the below mentioned person. I have also been informed that I can refuse to participate or terminate the interview, if I don't want to participate, at any time during the study.

இந்த நேர்காணல் பற்றிய கூடுதல் கேள்விகள்; ஏதேனும் என்னிடம் இருந்தால் கீழே குறிப்பிடப்பட்ட நபரை என்னால் தொடர்பு கொள்ள முடியும் என்பதை நான் அறிவேன். இந்த ஆய்வின் பொழுது எந்த நேரத்திலும் பங்கேற்க நான் விரும்பா விட்டால் இந்த நேர்காணலில் பங்கேற்பதற்கு நான் மறுக்க முடியும் அல்லது அந்த நேர்காணலை முடித்துக் கொள்ளவும் முடியும் என்றும் எனக்குத் தெரிவிக்கப்பட்டு இருக்கிறது.

The foregoing information has been read by me / read out to me and explained to me. Having understood this, I consent voluntarily to participate in the study and I have put my signature / thumb impression on the consent form.

மேலே குறிப்பிட்ட தகவல்கள் என்னால் படித்து பார்க்கப்பட்டன/எனக்குப் படித்து காட்டப்பட்டன மற்றும் விளக்கப்பட்டன. இதைப் புரிந்து கொண்டு நான் இந்த ஆய்வில் பங்கேற்பதற்கு தன்னிச்சையாக சம்மதம் அளிக்கிறேன் மற்றும் இந்த சம்மதப் படிவத்தில் எனது கையொப்பத்தை/கட்டை விரல் பதிவை இட்டிருக்கிறேன்.

Signature / thumb impression of the participant
பங்கேற்பவரின் கையொப்பம்/கட்டை விரல் பதிவு

Print name of the participant:

Date:

பங்கேற்பாளரின் பெயரை அச்சிடுக:

தேதி:

Witness if required:

I have witnessed the accurate reading of the consent form to the participant and the individual had the opportunity to ask questions. I confirm that the individual has given consent freely and voluntarily.

சாட்சி தேவைப்பட்டால்:

பங்கேற்பாளரிடம் சம்மதப்படிவம் துல்லியமாகப் படித்து காட்டப்பட்டதை நான் நேரில் கண்ணால் பார்த்தேன் மற்றும் அந்த நபருக்கு கேள்விகள் கேட்பதற்கு வாய்ப்பு கொடுக்கப்பட்டது. அந்த நபர் தனது சம்மதத்தை சுதந்திரமாகவும் தன்னிச்சையாகவும் அளித்திருக்கிறார் என்று நான் உறுதி செய்கிறேன்.

Signature / thumb impression of the witness
சாட்சியாளரின் கையொப்பம்/கட்டை விரல் பதிவு

Print name of the witness:

Date:

சாட்சியாளரின் பெயரை அச்சிடுக:

தேதி:

Statement by the researcher / person taking consent:

I have accurately read out the information sheet to the participant and to do the best of my ability, made sure that the participant understood what was told. I confirm that the participant had given consent freely and voluntarily.

சம்மதத்தைப் பெறும் ஆராய்ச்சியாளரின்/நபரின் அறிக்கை:

நான் இந்த தகவல் தாளை பங்கேற்பாளரிடம் துல்லியமாக வாசித்துக் காட்டியிருக்கிறேன் மற்றும் எனது சிறந்த அறிவுக்கேற்ப நான் கூறியதை அந்த பங்கேற்பாளர் புரிந்து கொள்வதையும் உறுதி செய்திருக்கிறேன். பங்கேற்பாளர் தனது சம்மதத்தை சுதந்திரமாகவும் தன்னிச்சையாகவும் அளித்திருந்தார் என்று நான் உறுதி செய்கிறேன்.

A copy of the informed consent form had been provided to the participant
தகவல் தெரிவிக்கப்பட்ட சம்மதப் படிவத்தின் பிரதி ஒன்று அந்த பங்கேற்பாளருக்கு அளிக்கப்பட்டு இருந்தது.

Signature of the researcher / person taking consent:
சம்மதத்தைப் பெறும் ஆராய்ச்சியாளரின்/நபரின் கையொப்பம்

Print name of the researcher / person taking consent:

Date:

சம்மதத்தைப் பெறும் ஆராய்ச்சியாளரின்/நபரின் பெயரை அச்சிடுக:

தேதி:

Phase – 2

Study title: Development of a Smartphone-enabled carer-supported educational intervention for management of disabilities following stroke in India

ஆய்வு தலைப்பு: இந்தியாவில் பக்கவாதம் பாதித்ததை தொடர்ந்து ஏற்படும் செயலிழப்புகளை சமாளிக்க, ஒரு ஸ்மார்ட்போன் துணையுடன், கவனிப்பாளரின் ஆதரவுடன் செயல்படுத்தப்பட்ட கல்விமுறையிலான மறுவாழ்வு சிகிச்சையின் உருவாக்கம்.

Participant Information Sheet
பங்கேற்பாளர் தகவல் தாள்

Dear Sir/Madam,
அன்புள்ள ஐயா/அம்மா,

Namaskar, My name is Suresh Kumar and I am a research degree student at the London School of Hygiene and Tropical Medicine (United Kingdom).

வணக்கம், எனது பெயர் சுரேஷ் குமார். லண்டன் ஸ்கூல் ஆஃப் ஹைஜீன் அன்ட் டிராபிக்கல் மெடிசின் (யுனைட்டெட் கிங்டம்) என்னும் கல்வி நிறுவனத்தில் நான் ஒரு ஆராய்ச்சி (முனைவர்) பட்டதாரி மாணவனாக இருக்கிறேன்.

Purpose of the study:

This study will assist in developing a Smartphone-enabled carer-supported educational intervention for disabilities following stroke that could potentially help meet the rehabilitation needs of stroke survivors and their caregivers. The purpose of this study is to understand the experiences of stroke survivors and their caregivers in using a smartphone-enabled carer-supported educational intervention for managing their physical disabilities and the operational difficulties that they encounter during the utilisation of this intervention.

இந்த ஆய்வின் நோக்கம்:

இந்த ஆய்வானது பக்கவாதத்தால் ஏற்படும் செயலிழப்புகளை சமாளிப்பதற்கான ஒரு ஸ்மார்ட்போன் துணையுடன், கவனிப்பாளரின் ஆதரவுடன் செயல்படுத்தப்பட்ட கல்விமுறையிலான புனர்வாழ்வு சிகிச்சை ஒன்றை உருவாக்க துணை புரியும். இந்த ஆய்வு பக்கவாதம் வந்து உயிர் பிழைத்தவர்களின் புனர்வாழ்வு தேவைகளையும் அவர்களை கவனித்து கொள்பவரின் தேவைகளையும் பூர்த்திசெய்ய உதவும் என எதிர்பார்க்கப்படுகிறது. இந்த ஆய்வின் நோக்கமானது பக்கவாதத்தால் பாதிக்கப்பட்டவர் மற்றும் அவரை பார்த்துக்கொள்பவர் ஒரு ஸ்மார்ட்போன் துணையுடன், கவனிப்பாளரின் ஆதரவுடன் செயல்படுத்தப்பட்ட கல்விமுறையிலான மறுவாழ்வு சிகிச்சை முறையை பயன்படுத்துவதின் அனுபவங்களையும் குறிப்பாக பயன்படுத்த முயலும் போது எதிர்கொள்ளும் சிரமங்களையும் கண்டறிவதே ஆகும்.

Questions and Concerns:

You are being invited to participate in this study. Kindly read / listen to this information attentively. If you are not clear about anything or if there is any uncertainty, then you are free to ask any questions to me. Please sign the consent letter only when you are able to understand the nature of this study and your rights as a participant. You are free to discuss it with anybody, whose

consultation is important to you.

கேள்விகள் மற்றும் சந்தேகங்கள்:

இந்த ஆய்வில் பங்கேற்பதற்காக நீங்கள் அழைக்கப்பட்டுள்ளீர்கள். அன்புகூர்ந்து இந்த தகவல்களை கவனமாக படியுங்கள்/கேளுங்கள். உங்களுக்கு ஏதேனும் தெளிவாக விளங்கவில்லை என்றாலும் அல்லது ஏதாவது ஐயமிருந்தாலும், அதைபற்றி என்னிடம் கேட்பதற்கு உங்களுக்கு அனைத்து சுதந்திரமும் உள்ளது. இந்த ஆய்வின் தன்மை பற்றியும், ஒரு பங்கேற்பாளராக உங்களது உரிமைகள் பற்றியும் உங்களால் புரிந்துகொள்ள முடிந்தால் மட்டுமே, இந்த சம்மதக் கடிதத்தில் உங்கள் கையொப்பத்தை இடுமாறு உங்களை கேட்டுக்கொள்கிறேன். யாருடனாவது கலந்தாலோசிப்பது முக்கியம் என்று நீங்கள் கருதுகின்ற யாரிடமும், நீங்கள் இது பற்றி விவாதிப்பதற்கு உங்களுக்கு சுதந்திரம் இருக்கிறது.

Voluntary Participation:

It is entirely your decision to participate in this study. If you want to discontinue at any point of time, you are free to do so without stating any reason. Your non- participation will not be held against you in any manner.

தன்னிச்சையான பங்கேற்பு:

இந்த ஆய்வில் பங்கேற்பது என்பது முழுவதுமாக உங்களது முடிவே ஆகும். எந்த நேரத்திலாவது நீங்கள் இந்த ஆய்வில் இருந்து விலக விரும்பினால், காரணம் எதையும் கூறாமல் விலகுவதற்கு உங்களுக்கு முழு சுதந்திரம் உள்ளது. நீங்கள் பங்கேற்காமல் போனால் கூட உங்களுக்கு எதிராக எந்த முறையிலும் எவ்விதமான நடவடிக்கையும் இருக்காது.

What it means to participate?

As a part of this study, we intend to develop a web-based application that will contain videos related to management of physical disabilities at home following a stroke. In order to make this application user friendly and appealing, we propose to provide this intervention along with the smartphone to stroke survivors and request them to use it with the support or help of their primary caregiver at their home for two weeks. In case you feel uncomfortable while using the intervention in these two weeks, you can decide not to continue at all at any point of time. If you have any queries regarding the study, you can contact me at any time on the number mentioned in the last page of this information sheet. The information that you will provide us during the study will be kept confidential and it will be used only for research study purposes without disclosing your personal identity.

இந்த ஆய்வில் பங்கேற்பது என்பதன் பொருள் என்ன?

இந்த ஆய்வில், பக்கவாதத்தால் பாதிக்கப்பட்டவர், தனக்கு பக்கவாதத்தால் ஏற்படும் உடல் இயலாமைகளை வீட்டிலேயே தானாகவே அல்லது தன்னை கவனித்து கொள்பவரின் துணை கொண்டு எப்படி சமாளிக்கலாம் என்பது பற்றிய விஷயங்களை வீடியோ காட்சிகளாக தயாரித்து, அதை ஒரு படம்-பார்க்க கூடிய செல்போனில் போட்டு, பாதிக்கப்பட்டவர் பயன்படுத்துவதற்கு உதவுவதே ஆகும். இந்த கல்விரீதியிலான சிகிச்சையை, பாதிக்கப்பட்டவர் மற்றும் அவரை பார்த்து கொள்பவர் எளிதில் பயன்படுத்தி, தனக்கு பக்கவாதத்தால் ஏற்பட்ட இயலாமைகளை திறம்பட சமாளிப்பதற்காக. ஒரு படம் பார்க்க கூடிய செல் போனில் போட்டு அதை பாதிக்கப்பட்டவர் சுமார் ஒரு இரண்டு வாரம் தன்

வீட்டிலேயே பயன்படுத்துமாறு கேட்டு கொள்ள படுவர். நீங்கள் இந்த ஆய்வில் பங்கேற்கும் போது, உங்களுக்கு சவுகரியமாக இல்லையென்றால், இதற்கு மேல் பங்கேற்க விருப்பமில்லை என்று சொல்லி தாராளமாக உங்கள் பங்கேற்பை முடித்து கொள்ளலாம். உங்களுக்கு இந்த ஆய்வு பற்றி ஏதாவது சந்தேகமோ கேள்வியோ இருந்தால், இந்த தகவல் தாளில் குறிப்பிடப்பட்டிருக்கும் முகவரி அல்லது தொலைபேசி எண்ணில் என்னை தொடர்பு கொள்ளலாம். இந்த ஆய்வில் உங்களிடமிருந்து பெறப்படும் தகவல்கள் யாவையும் ரகசியமாக வைக்கப்படும் மற்றும் ஆய்வு நோக்கங்களுக்காக மட்டுமே, உங்களது தனிப்பட்ட அடையாளத்தை வெளிப்படுத்தாமல் பயன்படுத்தப்படும்.

Future studies:

Based on the findings from the present study, I would conduct further studies. Thus I would like to invite you to continue to participate in the future, if you wish.

எதிர்கால ஆய்வுகள்:

இந்த தற்பொழுதைய ஆய்வில் கண்டுபிடித்தவைகளின் அடிப்படையில் கூடுதல் ஆய்வுகளை நான் நடத்துவேன். இதில் நீங்கள் கலந்துகொள்ள விரும்பினால் எதிர்காலத்தில் தொடர்ந்து பங்கேற்பதற்கு நான் உங்களை வரவேற்கிறேன்.

Risk of participating in the study:

I do not expect that you will incur any risks by participating in the study.

இந்த ஆய்வில் பங்கேற்பதன் அபாயம்:

இந்த ஆய்வில் பங்கேற்பதால் உங்களுக்கு எந்தவித அபாயமும் இருக்காது.

Confidentiality:

If you decide to participate in the study, all details provided by you will be kept confidential and it will be made available to the research investigators related to this study. Information collected from you will be stored securely in a locked cabinet and a password protected computer. The results will be published in research magazines and reports. However the names and personal details of the study participants will not be disclosed and you will not be recognized from them.

ஆய்வின் ரகசியத்தன்மை:

இந்த ஆய்வில் பங்கேற்பதற்கு நீங்கள் முடிவு செய்தால் உங்களால் தரப்படும் அனைத்து விபரங்களும்/புகைப்படங்கள் ரகசியமாக வைக்கப்படும் மற்றும் அவை இந்த ஆய்வு தொடர்பான விஷயங்களுக்கு மட்டுமே பயன்படுத்தப்படும். உங்களிடமிருந்து சேகரிக்கப்பட்ட விவரங்கள் பூட்டிய பெட்டகம் ஒன்றிலும், கடவுச் சொல் கொண்டு பாதுகாக்கப்பட்ட கணினியிலும் பத்திரமாக சேமித்து வைக்கப்படும். ஆய்வில் பங்கேற்றவர்களின் பெயர்கள் மற்றும் தனிப்பட்ட விபரங்கள் யாருக்கும் வெளிக்காட்ட பட மாட்டாது.

Funding

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நிதி பெறுதல்:

இந்த ஆய்வுக்கான நிதி வெல்கம் டிரஸ்ட்-பப்ளிக் ஹெல்த் ஃபவுண்டேசன் ஆஃப் இந்தியா என்ற அமைப்பின், கெப்பசிட்டி பில்டிங் ஸ்ட்ரீட்டிஜிக் அவார்ட் மூலம் அளிக்கப்படுகிறது.

Contact for further information:

If you have any questions, please contact Suresh Kumar at the Indian Institute of Public Health, Plot no: 1, ANV Arcade, Amar co-op Society, Kavuri Hills, Madhapur, Hyderabad. Phone: 040-49006050, Mobile: 0091- 9840772381.

கூடுதல் தகவல்களுக்கு தொடர்பு கொள்ளுங்கள்:

உங்களிடம் கேள்விகள் ஏதேனும் இருந்தால் இந்தியன் இன்ஸ்டிடியூட் ஆஃப் பப்ளிக் ஹெல்த்இ பிளாட் எண்: 1 ஏஎன்வி ஆர்க்கேட் அமர் கோ-ஆப் சொஸைட்டி காவூரி ஹில்ஸ் மாதாப்பூர் ஹைதராபாத். தொலைபேசி எண்: 040 – 49006050 மொபைல் எண்: 0091- 9840772381. என்னும் முகவரியில் உள்ள சுரேஷ்குமாரை தயவுசெய்து தொடர்பு கொள்ளுங்கள்.

Information Sheet about stroke பக்கவாதம் பற்றிய தகவல் தாள்

What is Stroke?

A stroke occur when the blood supply to part of the brain is suddenly interrupted or when a blood vessel in the brain bursts, spilling blood into the spaces surrounding brain cells. Brain cells die when they no longer receive oxygen and nutrients from the blood or there is sudden bleeding into or around the brain. The symptoms of a stroke include sudden numbness or weakness, especially on one side of the body; sudden confusion or trouble speaking or understanding speech; sudden trouble seeing in one or both eyes; sudden trouble with walking, dizziness, or loss of balance or coordination; or sudden severe headache with no known cause. There are two forms of stroke: *ischemic* - blockage of a blood vessel supplying the brain, and *haemorrhagic* - bleeding into or around the brain.

பக்கவாதம் என்பது என்ன?

மூளையின் ஒரு பகுதிக்கு இரத்த வினியோகம் திடீரென்று தடைப்படும் பொழுது அல்லது மூளையில் உள்ள ஒரு இரத்த நாளம் வெடித்து சிதறி பாயும் இரத்தமானது மூளையின் செல்களை சுற்றிலும் உள்ள இடைவெளிகளுக்குள் பாயும் பொழுது பக்கவாதம் நேர்கிறது. இதனால் மூளை இயங்குவதற்கு தேவையான ஆக்ஸிஜனும் ஊட்டசத்தும் மூளைக்கு கிடைக்காத பட்சத்தில், மூளையின் செல்கள் இறந்துவிடுகின்றன. பக்கவாதத்தின் அறிகுறிகளாக திடீரென்று உடல் மறுத்துப் போவது அல்லது பலவீனமடைவது; குறிப்பாக உடலின் ஒரு பக்கத்தில் அது ஏற்படுவது; திடீர் குழப்பம், பேசுவதில் அல்லது பேச்சைப் புரிந்து கொள்வதில் சிரமம், ஒரு கண்ணால் அல்லது இரண்டு கண்களாலும் பார்ப்பதில் திடீரென்று சிரமம்; நடப்பதில் திடீரென்று சிரமம், தலைச்சுற்றல், உடலின் சமநிலையை அல்லது ஒருங்கிணைத்தலை இழப்பது; அறியப்படாத காரணத்தால் திடீரென்று தீவிரமான தலைவலி ஏற்படுவது. இவை அனைத்தும் பக்கவாதத்தின் அறிகுறிகளாகும். பக்கவாதத்தில் இரண்டு வகை உண்டு: ஒன்று இஸ்கீமிக் - மூளைக்கு இரத்தம் வினியோகிக்கும் நாளம் ஒன்றில் அடைப்பு ஏற்படுவது. மற்றொன்று ஹெமரேஜிக் - மூளையினுள் அல்லது மூளையைச் சுற்றிலும் இரத்தக்கசிவு ஏற்படுவது.

Is there any treatment?

Generally there are three treatment stages for stroke: prevention, therapy immediately after the stroke, and post-stroke rehabilitation. Therapies to prevent a first or recurrent stroke are based on treating an individual's underlying risk factors for stroke, such as hypertension, atrial fibrillation, and diabetes. Acute stroke therapies try to stop a stroke while it is happening by quickly dissolving the blood clot causing an ischemic stroke or by stopping the bleeding of a haemorrhagic stroke. Post-stroke rehabilitation helps individuals overcome disabilities that result from stroke damage. Medication or drug therapy is the most common treatment for stroke. The most popular classes of drugs used to prevent or treat stroke are antithrombotic (anti-platelet agents and anticoagulants) and thrombolytic.

இதற்கு சிகிச்சை எதுவும் இருக்கிறதா?

பொதுவாக பக்கவாதத்தை சமாளிப்பதில் மூன்று சிகிச்சை கட்டங்கள் உள்ளன: பக்கவாதம் வராமல் தடுப்பது, பக்கவாதம் நேர்ந்த உடனே சிகிச்சை அளிப்பது மற்றும் பக்கவாதத்திற்குப் பிந்தைய மறுவாழ்வு சிகிச்சை. முதல்முறை அல்லது அடுத்தடுத்து நேரும் பக்கவாதத்தை தடுப்பதற்கான சிகிச்சைகள், பக்கவாதம் நேர்வதற்கு அடிப்படையாக இருக்கும் அபாயக் காரணிகளான, மிக அதிகமான

இரத்த அழுத்தம், இதயம் சீரற்று துடிப்பது (ஏட்ரியல் ஃபைப்ரில்லேசன்) மற்றும் நீரிழிவு நோய் போன்றவற்றை குணப்படுத்துவதையே அடிப்படையாக கொண்டுள்ளது. பக்கவாதம் வந்த சில மணிநேரத்திலேயே கொடுக்கப்படும் திவிர சிகிச்சைகள் பக்கவாதம் ஒன்று நேரும் பொழுது துரிதமாக இரத்தக்கட்டியைக் கரைத்து (இஸ்கெமிக்), பக்கவாதம் ஏற்படுத்துவதைத் தடுத்தும் அல்லது இரத்தக்கசிவைத் தடுப்பதன் (ஹெமரஜிக்) மூலமாகவும் பக்கவாதம் நேர்வதைத் தடுக்க முயற்சிக்கிறது. பக்கவாதத்திற்குப் பிந்தைய மறுவாழ்வு ஆனது பக்கவாதத்தால் ஏற்படும் மூளை சேதத்தின் விளைவினால் நேரிடும் செயலிழப்புகளை சமாளிப்பதற்கு உதவுகிறது. பக்கவாதத்திற்கு மிக பொதுவான சிகிச்சை மருந்து அளிப்பதே ஆகும். பக்கவாதத்தைத் தடுப்பதற்கு அல்லது சிகிச்சைக்குப் பயன்படும் மிகவும் பிரபலமான மருந்துகளின் வகுப்புகள் ஆன்ட்டித்ராம்போட்டிக், ஆன்ட்டி-பிளேட்டெட் ஏஜென்டுகள் மற்றும் ஆன்ட்டிகோயாகுலன்டுகள் மற்றும் த்ராம்போலைட்டிக் ஆகியவை ஆகும்.

What is the prognosis?

Although stroke is a disease of the brain, it can affect the entire body. A common disability that results from stroke is complete paralysis on one side of the body, called *hemiplegia*. A related disability that is not as debilitating as paralysis is one-sided weakness or *hemiparesis*. Stroke may cause problems with thinking, awareness, attention, learning, judgment, and memory. Stroke survivors often have problems understanding or forming speech. A stroke can lead to emotional problems. Stroke patients may have difficulty controlling their emotions or may express inappropriate emotions. Many stroke patients experience depression. Stroke survivors may also have numbness or strange sensations. The pain is often worse in the hands and feet and is made worse by movement and temperature changes, especially cold temperatures. Recurrent stroke is frequent; about 25 percent of people who recover from their first stroke will have another stroke within 5 years.

நோய் பற்றிய முன்கணிப்பு

பக்கவாதம் என்பது மூளையின் ஒரு நோய் என்றாலும் கூட அது முழு உடலையும் பாதிக்கக்கூடியது ஆகும். பக்கவாதத்தினால் நேரிடும் ஒரு பொதுவான செயலிழப்பு, ஹெமிப்ளிஜியா என்று அழைக்கப்படும் அது, உடலின் ஒரு பக்கம் ஆனது முழுமையாக முடக்குவாதத்தால் செயலிழந்து போய்விடுவது ஆகும். இது போன்ற உடலின் ஒரு பக்கம், முடக்குவாதத்தால் பாதிக்கப்படாமல் பலவீனம் மட்டும் அடைவது ஹெமிபேரசிஸ் என்று அழைக்கப்படும். பக்கவாதம் ஆனது சிந்திப்பதில், விழிப்புணர்வில், கவனத்தில், கற்றுக் கொள்வதில், திறனாய்வு செய்வதில் மற்றும் ஞாபகத்தின் ஆகியவற்றில் பிரச்சினைகளை ஏற்படுத்தலாம். பக்கவாதம் வந்து பிழைத்தவர்களுக்கு பெரும்பாலும் பேச்சைப் புரிந்து கொள்வதில் அல்லது பேச்சை உருவாக்குவதில் பிரச்சினைகள் நேர்கின்றன. பக்கவாதம் ஆனது உணர்வு ரீதியான பிரச்சினைகளை கூட ஏற்படுத்தலாம். பக்கவாதம் வந்த நோயாளிகளுக்கு தங்களது உணர்வுகளைக் கட்டுப்படுத்துவதில் சிரமம் இருக்கலாம் அல்லது அவர்கள் பொருத்தமற்ற உணர்வுகளை வெளிப்படுத்தலாம். பக்கவாதம் வந்த பல நோயாளிகள் மனஅழுத்தத்தை அனுபவிக்கின்றனர். பக்கவாதம் வந்து உயிர் பிழைத்தவர்களுக்கு உடல் உணர்வின்மை (உடல் மறுத்து போவது) அல்லது வித்தியாசமான உணர்வுகளும் இருக்கலாம். பக்கவாதம் வந்தவருக்கு பொதுவாக, கைகள் மற்றும் பாதங்களில் அடிக்கடி வலி மோசமாக இருக்கும் மற்றும் அந்த வலியானது உடல் அசைவதாலும், வெப்பநிலை மாற்றங்களாலும் குறிப்பாக குளிர்ந்த வெப்பநிலைகளில் மோசமடைகிறது. ஒரு முறை பக்கவாதம் வந்தவருக்கு மறுமுறை பக்கவாதம் வருவதற்கு பெரிதும் வாய்ப்புள்ளது. முதல்முறை பக்கவாதத்தில் இருந்து மீள்பவர்களில் 25 சதவிகிதம் பேருக்கு 5 ஆண்டுகளுக்கு உள்ளாக அடுத்து ஒரு பக்கவாத தாக்குதல் நேரிட வாய்ப்புள்ளது.

Source: National Institute of neurological disorders and stroke

தகவல் மூலம்: நேசனல் இன்ஸ்டிடியூட் ஆஃப் நியூராலஜிக்கல் டிஸார்டர்ஸ் அன்ட் ஸ்ட்ரோக்

Informed Consent form
தகவல் தெரிவிக்கப்பட்ட சம்மதப் படிவம்

“Development of a Smartphone-enabled carer-supported educational intervention for management of disabilities following stroke in India”

“இந்தியாவில் பக்கவாதம் பாதித்ததை தொடர்ந்து ஏற்படும் செயலிழப்புகளை சமாளிக்க, ஒரு ஸ்மார்ட்போன் துணையுடன் கவனிப்பாளரின் ஆதரவுடன் செயல்படுத்தப்பட்ட கல்விமுறையிலான மறுவாழ்வு சிகிச்சையின் உருவாக்கம்”

I give my consent to Suresh Kumar, from the London School of Hygiene and Tropical Medicine (LSHTM) to participate in the study. It has been explained to me that my participation in this research study has educational value to stroke survivors and their caregivers and I therefore consent for receiving and using this educational intervention along with the smartphone (Micromax A102 IMEI Number _____ and SIM card Number _____ for two weeks.

இந்த ஆய்வில் நான் பங்கேற்க எனது சம்மதத்தை சுரேஷ்குமார் என்னும் லண்டன் ஸ்கூல் ஆஃப் ஹைஜீன் அன்ட் டிராபிக்ஸ் மெடிசின் (எல்எஸ்எச்டிஎம்) (LSHTM) என்னும் கல்வி நிறுவனத்தைச் சேர்ந்தவருக்கு தருகிறேன். இந்த ஆய்வில் எனது பங்கேற்பானது பக்கவாதத்தால் பாதிக்கப்பட்டவரின் மறுவாழ்வு பயிற்சிக்கு பயனுடையதாக இருக்கும் என்பதை நான் அறிவேன். ஆதலால் இந்த ஆய்வுக்காக நான் பயன்படுத்தி பார்பதற்கு கொடுக்கப்படும் ஸ்மார்ட் போன் (மைக்ரோமாக்ஸ் A102 IMEI நம்பர் _____ மற்றும் சிம் நம்பர் _____ கொண்ட கல்விரீதியிலான சிகிச்சை முறையை இரண்டு வாரம் நான் பயன்படுத்த சம்மதிக்கிறேன்.

I am completely aware that the smartphone and the accessories that will be provided to me as a part of this study is very expensive and I take complete responsibility of any damage and malfunction of the smartphone and its accessories including theft of the same, while I am using it during the study period. I also understand that, I will have to replace or repay for any damage, malfunction or theft of the smartphone and its accessories, while I am using it during the two weeks study period. I understand that efforts will be made to conceal my identity, but that full anonymity cannot be guaranteed.

இந்த ஆய்விற்காக எனக்கு கொடுக்கப்படும் ஸ்மார்ட் போன் மற்றும் அதன் துணை கருவிகள் அனைத்தும் விலை உயர்ந்த பொருட்கள் என்பதை நான் நன்கு அறிவேன். அதனால் இந்த ஆய்வில் எனக்கு கொடுக்கப்படும் இந்த ஸ்மார்ட் போன் மற்றும் அதன் துணை கருவிகள் இவற்றின் சேதம், செயலிழப்பு, திருட்டு ஆகிய பிரச்சனைகளுக்கு, இந்த சாதனங்களை ஆய்விற்காக நான் பயன்படுத்தும் இரு வாரம் வரை நானே முழு பொறுப்பு ஏற்கிறேன். ஆய்விற்காக இந்த சாதனங்களை நான் பயன்படுத்தும் இரு வாரத்திற்குள் இந்த ஸ்மார்ட் போன் மற்றும் அதன் துணை கருவிகள் சேதமடைதாலோ, செயலிழந்தாலோ, திருட்டு போனாலோ அதை பணமாக இல்லையென்றால் அதே பொருளை புதிதாக வாங்கி கொடுத்து ஈடுகட்ட வேண்டும் என்பதை நான் நன்கு அறிவேன். இந்த ஆய்வுக்காக உதவும் என்னை பற்றிய தகவல்கள், எனது அடையாளங்களான; பெயர், முகவரி, என் பிரச்சனைகள், இவை அனைத்தையும் எந்த வகையிலும் மற்றவருக்கு வெளிபடுத்தாமல் வைத்திருக்கப்படும் என்பதையும் நான் அறிவேன்.

I confirm that the purpose of my participation in this study has been explained to me. It has been made clear to me that refusal to consent will in no way affect my medical care and rehabilitation. I confirm that I am of sound mind and that I am not signing under any form of duress.

இந்த ஆய்வில் எனது பங்கேற்பின் பயன் என்ன என்பது எனக்கு விளக்கமாக சொல்லப்பட்டது என்பதை நான் உறுதி செய்கிறேன். இந்த ஆய்வுக்காக எனது சம்மதத்தை நான் தர மறுத்தால் அது எந்த வகையிலும் எனது மருத்துவ சிகிச்சை மற்றும் மறுவாழ்வு சிகிச்சையை பாதிக்காது என்பது எனக்கு தெளிவாக எடுத்துரைக்கப்பட்டுள்ளது. நான் என் சம்மதத்தை மனபூர்வமாகவும், எந்த வற்புறுத்தலும் இல்லாமல் தருகிறேன் என்பதை உறுதி செய்கிறேன்.

I am aware if I have any further enquiries, I can contact the below mentioned person. I have also been informed that I can refuse to participate or terminate the session, if I don't want to participate, at any time during the study.

இந்த ஆய்வை பற்றிய கூடுதல் கேள்விகள், ஏதேனும் என்னிடம் இருந்தால் கீழே குறிப்பிடப்பட்ட நபரை என்னால் தொடர்பு கொள்ள முடியும் என்பதை நான் அறிவேன். இந்த ஆய்வின் பொழுது எந்த நேரத்திலும் பங்கேற்க நான் விரும்பாவிட்டால் நான் பங்கேற்பதற்கு மறுக்கவோ அல்லது எனது பங்கேற்பை முடித்துக்கொள்ளவோ முடியும் என்றும் எனக்குத் தெரிவிக்கப்பட்டு இருக்கிறது.

The foregoing information has been read by me / read out to me and explained to me. Having understood this, I consent voluntarily to participate in the study and I have put my signature / thumb impression on the consent form.

மேலே குறிப்பிட்ட தகவல்கள் என்னால் படித்து பார்க்கப்பட்டன அல்லது எனக்குப் படித்து காட்டப்பட்டன மற்றும் விளக்கப்பட்டன. இதைப் புரிந்து கொண்டு நான் இந்த ஆய்வில் பங்கேற்பதற்கு தன்னிச்சையாக சம்மதம் அளிக்கிறேன் மற்றும் இந்த சம்மதப் படிவத்தில் எனது கையொப்பத்தை/கட்டை விரல் பதிவை இட்டிருக்கிறேன்.

Signature / thumb impression of the participant
பங்கேற்பவரின் கையொப்பம்/கட்டை விரல் பதிவு

Print name of the participant:

Date:

பங்கேற்பாளரின் பெயரை அச்சிடுக:

தேதி:

Witness if required:

I have witnessed the accurate reading of the consent form to the participant and the individual had the opportunity to ask questions. I confirm that the individual has given consent freely and voluntarily.

சாட்சி தேவைப்பட்டால்:

பங்கேற்பாளரிடம் சம்மதப்படிவம் துல்லியமாகப் படித்து காட்டப்பட்டதை நான் நேரில் கண்ணால் பார்த்தேன் மற்றும் அந்த நபருக்கு கேள்விகள் கேட்பதற்கு வாய்ப்பு கொடுக்கப்பட்டது. அந்த நபர் தனது சம்மதத்தை சுதந்திரமாகவும் தன்னிச்சையாகவும் அளித்திருக்கிறார் என்று நான் உறுதி செய்கிறேன்.

Signature / thumb impression of the witness
சாட்சியாளரின் கையொப்பம்/கட்டை விரல் பதிவு

Print name of the witness:

Date:

சாட்சியாளரின் பெயரை

அச்சிடுக:

தேதி:

Statement by the researcher / person taking consent:

I have accurately read out the information sheet to the participant and to do the best of my ability, made sure that the participant understood what was told. I confirm that the participant had given consent freely and voluntarily.

சம்மதத்தைப் பெறும் ஆராய்ச்சியாளரின்/நபரின் அறிக்கை:

நான் இந்த தகவல் தாளை பங்கேற்பாளரிடம் துல்லியமாக வாசித்துக் காட்டியிருக்கிறேன் மற்றும் எனது சிறந்த அறிவுக்கேற்ப நான் கூறியதை அந்த பங்கேற்பாளர் புரிந்து கொள்வதையும் உறுதி செய்திருக்கிறேன். பங்கேற்பாளர் தனது சம்மதத்தை சுதந்திரமாகவும் தன்னிச்சையாகவும் அளித்திருந்தார் என்று நான் உறுதி செய்கிறேன்.

A copy of the informed consent form had been provided to the participant

தகவல் தெரிவிக்கப்பட்ட சம்மதப் படிவத்தின் பிரதி ஒன்று அந்த பங்கேற்பாளருக்கு அளிக்கப்பட்டு இருந்தது.

Signature of the researcher / person taking consent:
சம்மதத்தைப் பெறும் ஆராய்ச்சியாளரின்/நபரின் கையொப்பம்

Print name of the researcher / person taking consent:

Date:

சம்மதத்தைப் பெறும் ஆராய்ச்சியாளரின்/நபரின் பெயரை அச்சிடுக:

தேதி:

Phase – 3

Study title: Development of a Smartphone-enabled carer-supported educational intervention for management of disabilities following stroke in India

ஆய்வு தலைப்பு: இந்தியாவில் பக்கவாதம் பாதித்ததை தொடர்ந்து ஏற்படும் செயலிழப்புகளை சமாளிக்க, ஒரு ஸ்மார்ட்போன் துணையுடன், கவனிப்பாளரின் ஆதரவுடன் செயல்படுத்தப்பட்ட கல்விமுறையிலான மறுவாழ்வு சிகிச்சையின் உருவாக்கம்.

Participant Information Sheet

பங்கேற்பாளர் தகவல் தாள்

Dear Sir/Madam,
அன்புள்ள ஐயா/அம்மா,

Namaskar, My name is Suresh Kumar and I am a research degree student at the London School of Hygiene and Tropical Medicine (United Kingdom).

வணக்கம், எனது பெயர் சுரேஷ் குமார். லண்டன் ஸ்கூல் ஆஃப் ஹைஜீன் அன்ட் டிராபிக்கல் மெடிசின் (யுனைட்டெட் கிங்டம்) என்னும் கல்வி நிறுவனத்தில் நான் ஒரு ஆராய்ச்சி (முனைவர்) பட்டதாரி மாணவனாக இருக்கிறேன்.

Purpose of the study:

This study will assist in developing a Smartphone-enabled carer-supported educational intervention for disabilities following stroke that could potentially help meet the rehabilitation needs of stroke survivors and their caregivers. The purpose of this study is to understand the experiences of stroke survivors and their caregivers in using a smartphone-enabled carer-supported educational intervention for managing their physical disabilities following stroke and the feasibility and acceptability of using this intervention.

இந்த ஆய்வின் நோக்கம்:

இந்த ஆய்வானது பக்கவாதத்தால் ஏற்படும் செயலிழப்புகளை சமாளிப்பதற்கான ஒரு ஸ்மார்ட்போன் துணையுடன், கவனிப்பாளரின் ஆதரவுடன் செயல்படுத்தப்பட்ட கல்விமுறையிலான மறுவாழ்வு சிகிச்சை ஒன்றை உருவாக்க துணை புரியும். இந்த ஆய்வு பக்கவாதம் வந்து உயிர் பிழைத்தவர்களின் மறுவாழ்வு தேவைகளையும் அவர்களை கவனித்து கொள்பவரின் தேவைகளையும் பூர்த்திசெய்ய உதவும் என எதிர்பார்க்கப்படுகிறது. இந்த ஆய்வின் நோக்கமானது, பக்கவாதத்தால் பாதிக்கப்பட்டவர் மற்றும் அவரை பார்த்துக்கொள்பவர் ஒரு ஸ்மார்ட்போன் துணையுடன், கவனிப்பாளரின் ஆதரவுடன் செயல்படுத்தப்பட்ட கல்விமுறையிலான மறுவாழ்வு சிகிச்சை முறையை பயன்படுத்தி, பக்கவாதத்தால் தங்களுக்கு ஏற்பட்ட உடல் இயலாமைகளை சமாளிக்க முயன்ற அனுபவங்களையும் இப்படி பட்ட மறுவாழ்வு சிகிச்சை முறை, தாங்கள் பயன்படுத்த சாத்தியமானதாகவும், ஏற்று கொள்ளத்தக்கதாகவும் உள்ளதா என்பதை கண்டறிவதே ஆகும்.

Questions and Concerns:

You are being invited to participate in this study. Kindly read / listen to this information attentively. If you are not clear about anything or if there is any uncertainty, then you are free to ask any questions to me. Please sign the consent letter only when you are able to understand the nature of this study and your rights as a participant. You are free to discuss it with anybody, whose

consultation is important to you.

கேள்விகள் மற்றும் சந்தேகங்கள்:

இந்த ஆய்வில் பங்கேற்பதற்காக நீங்கள் அழைக்கப்பட்டுள்ளீர்கள். அன்புகூர்ந்து இந்த தகவல்களை கவனமாக படியுங்கள்/கேளுங்கள். உங்களுக்கு ஏதேனும் தெளிவாக விளங்கவில்லை என்றாலும் அல்லது ஏதாவது ஐயமிருந்தாலும், அதைபற்றி என்னிடம் கேட்பதற்கு உங்களுக்கு அனைத்து சுதந்திரமும் உள்ளது. இந்த ஆய்வின் தன்மை பற்றியும், ஒரு பங்கேற்பாளராக உங்களது உரிமைகள் பற்றியும் உங்களால் புரிந்துகொள்ள முடிந்தால் மட்டுமே, இந்த சம்மதக் கடிதத்தில் உங்கள் கையொப்பத்தை இடுமாறு உங்களை கேட்டுக்கொள்கிறேன். யாருடனாவது கலந்தாலோசிப்பது முக்கியம் என்று நீங்கள் கருதுகின்ற யாரிடமும், நீங்கள் இது பற்றி விவாதிப்பதற்கு உங்களுக்கு சுதந்திரம் இருக்கிறது.

Voluntary Participation:

It is entirely your decision to participate in this study. If you want to discontinue at any point of time, you are free to do so without stating any reason. Your non- participation will not be held against you in any manner.

தன்னிச்சையான பங்கேற்பு:

இந்த ஆய்வில் பங்கேற்பது என்பது முழுவதுமாக உங்களது முடிவே ஆகும். எந்த நேரத்திலாவது நீங்கள் இந்த ஆய்வில் இருந்து விலக விரும்பினால், காரணம் எதையும் கூறாமல் விலகுவதற்கு உங்களுக்கு முழு சுதந்திரம் உள்ளது. நீங்கள் பங்கேற்காமல் போனால் கூட உங்களுக்கு எதிராக எந்த முறையிலும் எவ்விதமான நடவடிக்கையும் இருக்காது.

What it means to participate?

As a part of this study, we intend to develop a web-based application that will contain videos related to management of physical disabilities at home following a stroke. In order to understand the feasibility and acceptability of using this intervention, we propose to provide this intervention along with the smartphone to stroke survivors and request them to use it with the support or help of their caregiver at their home for four weeks. In case you feel uncomfortable while using the intervention in these four weeks, you can decide not to continue at all at any point of time. If you have any queries regarding the study, you can contact me at any time on the number mentioned in the last page of this information sheet. The information that you will provide us during the study will be kept confidential and it will be used only for research study purposes without disclosing your personal identity.

இந்த ஆய்வில் பங்கேற்பது என்பதன் பொருள் என்ன?

இந்த ஆய்வில், பக்கவாதத்தால் பாதிக்கப்பட்டவர், தனக்கு பக்கவாதத்தால் ஏற்படும் உடல் இயலாமைகளை வீட்டிலேயே தன்னை கவனித்து கொள்பவரின் துணை கொண்டு எப்படி சமாளிக்கலாம் என்பது பற்றிய விஷயங்களை வீடியோ காட்சிகளாக தயாரித்து, அதை ஒரு படம்- பார்க்க கூடிய செல்போனில் போட்டு, பாதிக்கப்பட்டவர் பயன்படுத்துவதற்கு உதவுவதே ஆகும்.

இந்த கல்விரீதியிலான சிகிச்சையை, பாதிக்கப்பட்டவர் மற்றும் அவரை பார்த்து கொள்பவர் எளிதில் பயன்படுத்தி, தனக்கு பக்கவாதத்தால் ஏற்பட்ட இயலாமைகளை திறம்பட சமாளிப்பதற்காக. ஒரு படம் பார்க்க கூடிய செல் போனில் போட்டு அதை பாதிக்கப்பட்டவர் சுமார் ஒரு நான்கு வாரம் தன்

வீட்டிலேயே பயன்படுத்துமாறு கேட்டு கொள்ள படுவர். நீங்கள் இந்த ஆய்வில் பங்கேற்கும் போது, உங்களுக்கு சவுகரியமாக இல்லையென்றால், இதற்கு மேல் பங்கேற்க விருப்பமில்லை என்று சொல்லி தாராளமாக உங்கள் பங்கேற்பை முடித்து கொள்ளலாம். உங்களுக்கு இந்த ஆய்வு பற்றி ஏதாவது சந்தேகமோ கேள்வியோ இருந்தால், இந்த தகவல் தாளில் குறிப்பிடப்பட்டிருக்கும் முகவரி அல்லது தொலைபேசி எண்ணில் என்னை தொடர்பு கொள்ளலாம். இந்த ஆய்வில் உங்களிடமிருந்து பெறப்படும் தகவல்கள் யாவையும் ரகசியமாக வைக்கப்படும் மற்றும் ஆய்வு நோக்கங்களுக்காக மட்டுமே, உங்களது தனிப்பட்ட அடையாளத்தை வெளிப்படுத்தாமல் பயன்படுத்தப்படும்.

Future studies:

Based on the findings from the present study, I would conduct further studies. Thus I would like to invite you to continue to participate in the future, if you wish.

எதிர்கால ஆய்வுகள்:

இந்த தற்பொழுதைய ஆய்வில் கண்டுபிடித்தவைகளின் அடிப்படையில் கூடுதல் ஆய்வுகளை நான் நடத்துவேன். இதில் நீங்கள் கலந்துகொள்ள விரும்பினால் எதிர்காலத்தில் தொடர்ந்து பங்கேற்பதற்கு நான் உங்களை வரவேற்கிறேன்.

Risk of participating in the study:

I do not expect that you will incur any risks by participating in the study.

இந்த ஆய்வில் பங்கேற்பதன் அபாயம்:

இந்த ஆய்வில் பங்கேற்பதால் உங்களுக்கு எந்தவித அபாயமும் இருக்காது.

Confidentiality:

If you decide to participate in the study, all details provided by you will be kept confidential and it will be made available to the research investigators related to this study. Information collected from you will be stored securely in a locked cabinet and a password protected computer. The results will be published in research magazines and reports. However the names and personal details of the study participants will not be disclosed and you will not be recognized from them.

ஆய்வின் ரகசியத்தன்மை:

இந்த ஆய்வில் பங்கேற்பதற்கு நீங்கள் முடிவு செய்தால் உங்களால் தரப்படும் அனைத்து விபரங்களும்/புகைப்படங்கள் ரகசியமாக வைக்கப்படும் மற்றும் அவை இந்த ஆய்வு தொடர்பான விஷயங்களுக்கு மட்டுமே பயன்படுத்தப்படும். உங்களிடமிருந்து சேகரிக்கப்பட்ட விவரங்கள் பூட்டிய பெட்டகம் ஒன்றிலும், கடவுச் சொல் கொண்டு பாதுகாக்கப்பட்ட கணினியிலும் பத்திரமாக சேமித்து வைக்கப்படும். ஆய்வில் பங்கேற்றவர்களின் பெயர்கள் மற்றும் தனிப்பட்ட விபரங்கள் யாருக்கும் வெளிக்காட்ட பட மாட்டாது.

Funding

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நிதி பெறுதல்:

இந்த ஆய்வுக்கான நிதி வெல்கம் டிரஸ்ட்-பப்ளிக் ஹெல்த் ஃபவுண்டேசன் ஆஃப் இந்தியா என்ற அமைப்பின், கெப்பசிட்டி பில்டிங் ஸ்ட்ரீட்டிஜிக் அவார்ட் மூலம் அளிக்கப்படுகிறது.

Contact for further information:

If you have any questions, please contact Suresh Kumar at the Indian Institute of Public Health, Plot no: 1, ANV Arcade, Amar co-op Society, Kavuri Hills, Madhapur, Hyderabad. Phone: 040-49006050, Mobile: 0091- 9840772381.

கூடுதல் தகவல்களுக்கு தொடர்பு கொள்ளுங்கள்:

உங்களிடம் கேள்விகள் ஏதேனும் இருந்தால் இந்தியன் இன்ஸ்டிடியூட் ஆஃப் பப்ளிக் ஹெல்த்இ பிளாட் எண்: 1 ஏஎன்வி ஆர்க்கேட் அமர் கோ-ஆப் சொசைட்டி காவூரி ஹில்ஸ் மாதாப்பூர் ஹைதராபாத். தொலைபேசி எண்: 040 – 49006050 மொபைல் எண்: 0091- 9840772381. என்னும் முகவரியில் உள்ள சுரேஷ்குமாரை தயவுசெய்து தொடர்பு கொள்ளுங்கள்.

Information Sheet about stroke பக்கவாதம் பற்றிய தகவல் தாள்

What is Stroke?

A stroke occur when the blood supply to part of the brain is suddenly interrupted or when a blood vessel in the brain bursts, spilling blood into the spaces surrounding brain cells. Brain cells die when they no longer receive oxygen and nutrients from the blood or there is sudden bleeding into or around the brain. The symptoms of a stroke include sudden numbness or weakness, especially on one side of the body; sudden confusion or trouble speaking or understanding speech; sudden trouble seeing in one or both eyes; sudden trouble with walking, dizziness, or loss of balance or coordination; or sudden severe headache with no known cause. There are two forms of stroke: *ischemic* - blockage of a blood vessel supplying the brain, and *haemorrhagic* - bleeding into or around the brain.

பக்கவாதம் என்பது என்ன?

மூளையின் ஒரு பகுதிக்கு இரத்த வினியோகம் திடீரென்று தடைப்படும் பொழுது அல்லது மூளையில் உள்ள ஒரு இரத்த நாளம் வெடித்து சிதறி பாயும் இரத்தமானது மூளையின் செல்களை சுற்றிலும் உள்ள இடைவெளிகளுக்குள் பாயும் பொழுது பக்கவாதம் நேர்கிறது. இதனால் மூளை இயங்குவதற்கு தேவையான ஆக்ஸிஜனும் ஊட்டசத்தும் மூளைக்கு கிடைக்காத பட்சத்தில், மூளையின் செல்கள் இறந்துவிடுகின்றன. பக்கவாதத்தின் அறிகுறிகளாக திடீரென்று உடல் மறுத்துப் போவது அல்லது பலவீனமடைவது; குறிப்பாக உடலின் ஒரு பக்கத்தில் அது ஏற்படுவது; திடீர் குழப்பம், பேசுவதில் அல்லது பேச்சைப் புரிந்து கொள்வதில் சிரமம், ஒரு கண்ணால் அல்லது இரண்டு கண்களாலும் பார்ப்பதில் திடீரென்று சிரமம்; நடப்பதில் திடீரென்று சிரமம், தலைச்சுற்றல், உடலின் சமநிலையை அல்லது ஒருங்கிணைத்தலை இழப்பது; அறியப்படாத காரணத்தால் திடீரென்று தீவிரமான தலைவலி ஏற்படுவது. இவை அனைத்தும் பக்கவாதத்தின் அறிகுறிகளாகும். பக்கவாதத்தில் இரண்டு வகை உண்டு: ஒன்று இஸ்கீமிக் - மூளைக்கு இரத்தம் வினியோகிக்கும் நாளம் ஒன்றில் அடைப்பு ஏற்படுவது. மற்றொன்று ஹெமரேஜிக் - மூளையினுள் அல்லது மூளையைச் சுற்றிலும் இரத்தக்கசிவு ஏற்படுவது.

Is there any treatment?

Generally there are three treatment stages for stroke: prevention, therapy immediately after the stroke, and post-stroke rehabilitation. Therapies to prevent a first or recurrent stroke are based on treating an individual's underlying risk factors for stroke, such as hypertension, atrial fibrillation, and diabetes. Acute stroke therapies try to stop a stroke while it is happening by quickly dissolving the blood clot causing an ischemic stroke or by stopping the bleeding of a haemorrhagic stroke. Post-stroke rehabilitation helps individuals overcome disabilities that result from stroke damage. Medication or drug therapy is the most common treatment for stroke. The most popular classes of drugs used to prevent or treat stroke are antithrombotic (anti-platelet agents and anticoagulants) and thrombolytic.

இதற்கு சிகிச்சை எதுவும் இருக்கிறதா?

பொதுவாக பக்கவாதத்தை சமாளிப்பதில் மூன்று சிகிச்சை கட்டங்கள் உள்ளன: பக்கவாதம் வராமல் தடுப்பது, பக்கவாதம் நேர்ந்த உடனே சிகிச்சை அளிப்பது மற்றும் பக்கவாதத்திற்குப் பிந்தைய மறுவாழ்வு சிகிச்சை. முதல்முறை அல்லது அடுத்தடுத்து நேரும் பக்கவாதத்தை தடுப்பதற்கான சிகிச்சைகள், பக்கவாதம் நேர்வதற்கு அடிப்படையாக இருக்கும் அபாயக் காரணிகளான, மிக அதிகமான

இரத்த அழுத்தம், இதயம் சீரற்று துடிப்பது (ஏட்ரியல் ஃபைப்ரில்லேசன்) மற்றும் நீரிழிவு நோய் போன்றவற்றை குணப்படுத்துவதையே அடிப்படையாக கொண்டுள்ளது. பக்கவாதம் வந்த சில மணிநேரத்திலேயே கொடுக்கப்படும் திவிர சிகிச்சைகள் பக்கவாதம் ஒன்று நேரும் பொழுது துரிதமாக இரத்தக்கட்டியைக் கரைத்து (இஸ்கெமிக்), பக்கவாதம் ஏற்படுத்துவதைத் தடுத்தும் அல்லது இரத்தக்கசிவைத் தடுப்பதன் (ஹெமரஜிக்) மூலமாகவும் பக்கவாதம் நேர்வதைத் தடுக்க முயற்சிக்கிறது. பக்கவாதத்திற்குப் பிந்தைய மறுவாழ்வு ஆனது பக்கவாதத்தால் ஏற்படும் மூளை சேதத்தின் விளைவினால் நேரிடும் செயலிழப்புகளை சமாளிப்பதற்கு உதவுகிறது. பக்கவாதத்திற்கு மிக பொதுவான சிகிச்சை மருந்து அளிப்பதே ஆகும். பக்கவாதத்தைத் தடுப்பதற்கு அல்லது சிகிச்சைக்குப் பயன்படும் மிகவும் பிரபலமான மருந்துகளின் வகுப்புகள் ஆன்ட்டித்ராம்போட்டிக், ஆன்ட்டி-பிளேட்டெட் ஏஜென்டுகள் மற்றும் ஆன்ட்டிகோயாகுலன்டுகள் மற்றும் த்ராம்போலைட்டிக் ஆகியவை ஆகும்.

What is the prognosis?

Although stroke is a disease of the brain, it can affect the entire body. A common disability that results from stroke is complete paralysis on one side of the body, called *hemiplegia*. A related disability that is not as debilitating as paralysis is one-sided weakness or *hemiparesis*. Stroke may cause problems with thinking, awareness, attention, learning, judgment, and memory. Stroke survivors often have problems understanding or forming speech. A stroke can lead to emotional problems. Stroke patients may have difficulty controlling their emotions or may express inappropriate emotions. Many stroke patients experience depression. Stroke survivors may also have numbness or strange sensations. The pain is often worse in the hands and feet and is made worse by movement and temperature changes, especially cold temperatures. Recurrent stroke is frequent; about 25 percent of people who recover from their first stroke will have another stroke within 5 years.

நோய் பற்றிய முன்கணிப்பு

பக்கவாதம் என்பது மூளையின் ஒரு நோய் என்றாலும் கூட அது முழு உடலையும் பாதிக்கக்கூடியது ஆகும். பக்கவாதத்தினால் நேரிடும் ஒரு பொதுவான செயலிழப்பு, ஹெமிப்ளிஜியா என்று அழைக்கப்படும் அது, உடலின் ஒரு பக்கம் ஆனது முழுமையாக முடக்குவாதத்தால் செயலிழந்து போய்விடுவது ஆகும். இது போன்ற உடலின் ஒரு பக்கம், முடக்குவாதத்தால் பாதிக்கப்படாமல் பலவீனம் மட்டும் அடைவது ஹெமிபேரசிஸ் என்று அழைக்கப்படும். பக்கவாதம் ஆனது சிந்திப்பதில், விழிப்புணர்வில், கவனத்தில், கற்றுக் கொள்வதில், திறனாய்வு செய்வதில் மற்றும் ஞாபகத்திறன் ஆகியவற்றில் பிரச்சினைகளை ஏற்படுத்தலாம். பக்கவாதம் வந்து பிழைத்தவர்களுக்கு பெரும்பாலும் பேச்சைப் புரிந்து கொள்வதில் அல்லது பேச்சை உருவாக்குவதில் பிரச்சினைகள் நேர்கின்றன. பக்கவாதம் ஆனது உணர்வு ரீதியான பிரச்சினைகளை கூட ஏற்படுத்தலாம். பக்கவாதம் வந்த நோயாளிகளுக்கு தங்களது உணர்வுகளைக் கட்டுப்படுத்துவதில் சிரமம் இருக்கலாம் அல்லது அவர்கள் பொருத்தமற்ற உணர்வுகளை வெளிப்படுத்தலாம். பக்கவாதம் வந்த பல நோயாளிகள் மனஅழுத்தத்தை அனுபவிக்கின்றனர். பக்கவாதம் வந்து உயிர் பிழைத்தவர்களுக்கு உடல் உணர்வின்மை (உடல் மறுத்து போவது) அல்லது வித்தியாசமான உணர்வுகளும் இருக்கலாம். பக்கவாதம் வந்தவருக்கு பொதுவாக, கைகள் மற்றும் பாதங்களில் அடிக்கடி வலி மோசமாக இருக்கும் மற்றும் அந்த வலியானது உடல் அசைவதாலும், வெப்பநிலை மாற்றங்களாலும் குறிப்பாக குளிர்ந்த வெப்பநிலைகளில் மோசமடைகிறது. ஒரு முறை பக்கவாதம் வந்தவருக்கு மறுமுறை பக்கவாதம் வருவதற்கு பெரிதும் வாய்ப்புள்ளது. முதல்முறை பக்கவாதத்தில் இருந்து மீள்பவர்களில் 25 சதவிகிதம் பேருக்கு 5 ஆண்டுகளுக்கு உள்ளாக அடுத்து ஒரு பக்கவாத தாக்குதல் நேரிட வாய்ப்புள்ளது.

Source: National Institute of neurological disorders and stroke

Informed Consent form
தகவல் தெரிவிக்கப்பட்ட சம்மதப் படிவம்

“Development of a Smartphone-enabled carer-supported educational intervention for management of disabilities following stroke in India”

“இந்தியாவில் பக்கவாதம் பாதித்ததை தொடர்ந்து ஏற்படும் செயலிழப்புகளை சமாளிக்க, ஒரு ஸ்மார்ட்போன் துணையுடன் கவனிப்பாளரின் ஆதரவுடன் செயல்படுத்தப்பட்ட கல்விமுறையிலான மறுவாழ்வு சிகிச்சையின் உருவாக்கம்”

I give my consent to Suresh Kumar, from the London School of Hygiene and Tropical Medicine (LSHTM) to participate in the study. It has been explained to me that my participation in this research study has educational value to stroke survivors and their caregivers and I therefore consent for receiving and using this educational intervention along with the smartphone (Micromax A102 IMEI Number _____ and SIM card Number _____ for four weeks.

இந்த ஆய்வில் நான் பங்கேற்க எனது சம்மதத்தை சுரேஷ்குமார் என்னும் லண்டன் ஸ்கூல் ஆஃப் ஹைஜீன் அன்ட் டிராபிக் கல் மெடிசின் (எல்எஸ்எச்டிஎம்) (LSHTM) என்னும் கல்வி நிறுவனத்தைச் சேர்ந்தவருக்கு தருகிறேன். இந்த ஆய்வில் எனது பங்கேற்பானது பக்கவாதத்தால் பாதிக்கப்பட்டவரின் மறுவாழ்வு பயிற்சிக்கு பயனுடையதாக இருக்கும் என்பதை நான் அறிவேன். ஆதலால் இந்த ஆய்வுக்காக நான் பயன்படுத்தி பார்பதற்கு கொடுக்கப்படும் ஸ்மார்ட் போன் (மைக்ரோமாக்ஸ் A102 IMEI நம்பர் _____ மற்றும் சிம் நம்பர் _____) கொண்ட கல்விரீதியிலான சிகிச்சை முறையை நான்கு வாரம் நான் பயன்படுத்த சம்மதிக்கிறேன்.

I am completely aware that the smartphone and the accessories that will be provided to me as a part of this study is very expensive and I take complete responsibility of any damage and malfunction of the smartphone and its accessories including theft of the same, while I am using it during the study period. I also understand that, I will have to replace or repay for any damage, malfunction or theft of the smartphone and its accessories, while I am using it during the four weeks study period. I understand that efforts will be made to conceal my identity, but that full anonymity cannot be guaranteed.

இந்த ஆய்விற்காக எனக்கு கொடுக்கப்படும் ஸ்மார்ட் போன் மற்றும் அதன் துணை கருவிகள் அனைத்தும் விலை உயர்ந்த பொருட்கள் என்பதை நான் நன்கு அறிவேன். அதனால் இந்த ஆய்வில் எனக்கு கொடுக்கப்படும் இந்த ஸ்மார்ட் போன் மற்றும் அதன் துணை கருவிகள் இவற்றின் சேதம், செயலிழப்பு, திருட்டு ஆகிய பிரச்சனைகளுக்கு, இந்த சாதனங்களை ஆய்விற்காக நான் பயன்படுத்தும் இரு வாரம் வரை நானே முழு பொறுப்பு ஏற்கிறேன். ஆய்விற்காக இந்த சாதனங்களை நான் பயன்படுத்தும் நான்கு வாரத்திற்குள் இந்த ஸ்மார்ட் போன் மற்றும் அதன் துணை கருவிகள் சேதமடைதாலோ, செயலிழந்தாலோ, திருட்டு போனாலோ அதை பணமாக இல்லையென்றால் அதே பொருளை புதிதாக வாங்கி கொடுத்து ஈடுகட்ட வேண்டும் என்பதை நான் நன்கு அறிவேன். இந்த ஆய்வுக்காக உதவும் என்னை பற்றிய தகவல்கள், எனது அடையாளங்களான; பெயர், முகவரி, என் பிரச்சனைகள், இவை அனைத்தையும் எந்த வகையிலும் மற்றவருக்கு வெளிப்படுத்தாமல்

வைத்திருக்கப்படும் என்பதையும் நான் அறிவேன்.

I confirm that the purpose of my participation in this study has been explained to me. It has been made clear to me that refusal to consent will in no way affect my medical care and rehabilitation. I confirm that I am of sound mind and that I am not signing under any form of duress.

இந்த ஆய்வில் எனது பங்கேற்பின் பயன் என்ன என்பது எனக்கு விளக்கமாக சொல்லப்பட்டது என்பதை நான் உறுதி செய்கிறேன். இந்த ஆய்வுக்காக எனது சம்மதத்தை நான் தர மறுத்தால் அது எந்த வகையிலும் எனது மருத்துவ சிகிச்சை மற்றும் மறுவாழ்வு சிகிச்சையை பாதிக்காது என்பது எனக்கு தெளிவாக எடுத்துரைக்கப்பட்டுள்ளது. நான் என் சம்மதத்தை மனபூர்வமாகவும், எந்த வற்புறுத்தலும் இல்லாமல் தருகிறேன் என்பதை உறுதி செய்கிறேன்.

I am aware if I have any further enquiries, I can contact the below mentioned person. I have also been informed that I can refuse to participate or terminate the session, if I don't want to participate, at any time during the study.

இந்த ஆய்வை பற்றிய கூடுதல் கேள்விகள்; ஏதேனும் என்னிடம் இருந்தால் கீழே குறிப்பிடப்பட்ட நபரை என்னால் தொடர்பு கொள்ள முடியும் என்பதை நான் அறிவேன். இந்த ஆய்வின் பொழுது எந்த நேரத்திலும் பங்கேற்க நான் விரும்பாவிட்டால் நான் பங்கேற்பதற்கு மறுக்கவோ அல்லது எனது பங்கேற்பை முடித்துக்கொள்ளவோ முடியும் என்றும் எனக்குத் தெரிவிக்கப்பட்டு இருக்கிறது.

The foregoing information has been read by me / read out to me and explained to me. Having understood this, I consent voluntarily to participate in the study and I have put my signature / thumb impression on the consent form.

மேலே குறிப்பிட்ட தகவல்கள் என்னால் படித்து பார்க்கப்பட்டன அல்லது எனக்குப் படித்து காட்டப்பட்டன மற்றும் விளக்கப்பட்டன. இதைப் புரிந்து கொண்டு நான் இந்த ஆய்வில் பங்கேற்பதற்கு தன்னிச்சையாக சம்மதம் அளிக்கிறேன் மற்றும் இந்த சம்மதப் படிவத்தில் எனது கையொப்பத்தை/கட்டை விரல் பதிவை இட்டிருக்கிறேன்.

Signature / thumb impression of the participant
பங்கேற்பவரின் கையொப்பம்/கட்டை விரல் பதிவு

Print name of the participant:

Date:

பங்கேற்பாளரின் பெயரை அச்சிடுக:

தேதி:

Witness if required:

I have witnessed the accurate reading of the consent form to the participant and the individual had the opportunity to ask questions. I confirm that the individual has given consent freely and voluntarily.

சாட்சி தேவைப்பட்டால்:

பங்கேற்பாளரிடம் சம்மதப்படிவம் துல்லியமாகப் படித்து காட்டப்பட்டதை நான் நேரில் கண்ணால் பார்த்தேன் மற்றும் அந்த நபருக்கு கேள்விகள் கேட்பதற்கு வாய்ப்பு கொடுக்கப்பட்டது. அந்த நபர் தனது சம்மதத்தை சுதந்திரமாகவும் தன்னிச்சையாகவும் அளித்திருக்கிறார் என்று நான் உறுதி செய்கிறேன்.

Signature / thumb impression of the witness
சாட்சியாளரின் கையொப்பம்/கட்டை விரல் பதிவு

Print name of the witness:

Date:

சாட்சியாளரின் பெயரை

அச்சிடுக:

தேதி:

Statement by the researcher / person taking consent:

I have accurately read out the information sheet to the participant and to do the best of my ability, made sure that the participant understood what was told. I confirm that the participant had given consent freely and voluntarily.

சம்மதத்தைப் பெறும் ஆராய்ச்சியாளரின்/நபரின் அறிக்கை:

நான் இந்த தகவல் தாளை பங்கேற்பாளரிடம் துல்லியமாக வாசித்துக் காட்டியிருக்கிறேன் மற்றும் எனது சிறந்த அறிவுக்கேற்ப நான் கூறியதை அந்த பங்கேற்பாளர் புரிந்து கொள்வதையும் உறுதி செய்திருக்கிறேன். பங்கேற்பாளர் தனது சம்மதத்தை சுதந்திரமாகவும் தன்னிச்சையாகவும் அளித்திருந்தார் என்று நான் உறுதி செய்கிறேன்.

A copy of the informed consent form had been provided to the participant

தகவல் தெரிவிக்கப்பட்ட சம்மதப் படிவத்தின் பிரதி ஒன்று அந்த பங்கேற்பாளருக்கு அளிக்கப்பட்டு இருந்தது.

Signature of the researcher / person taking consent:
சம்மதத்தைப் பெறும் ஆராய்ச்சியாளரின்/நபரின் கையொப்பம்

Print name of the researcher / person taking consent:

Date:

சம்மதத்தைப் பெறும் ஆராய்ச்சியாளரின்/நபரின் பெயரை அச்சிடுக:

தேதி:

Appendix 7

Smartphone Operations Manual

To Access ‘Care For Stroke’ Intervention

ILLUSTRATED OPERATIONS MANUAL TO ACCESS THE INTERVENTION FROM SMARTPHONE

செல் போனை பயன்படுத்தி இந்த சிகிச்சை முறைகளை
நீங்கள் பார்க்க உதவும் படங்கள் மூலம் உருவாக்கப்பட்ட
விளக்க கையேடு

உதவிக்கு எண் - (0) 9840772381 அழையுங்கள்

1



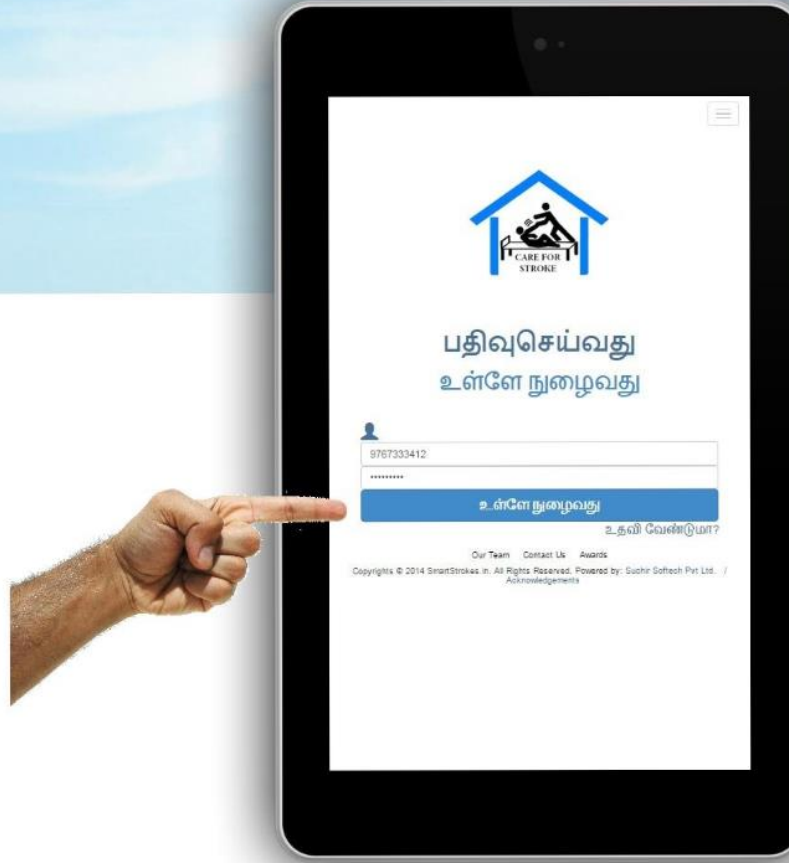
செல் போனில் சுட்டி காட்டப்பட்டுள்ள சின்ன படத்தை
தொடவும்

2



**செல் போனில் சுட்டி காட்டப்பட்டுள்ள சின்னத்தை
தொடவும்**

3



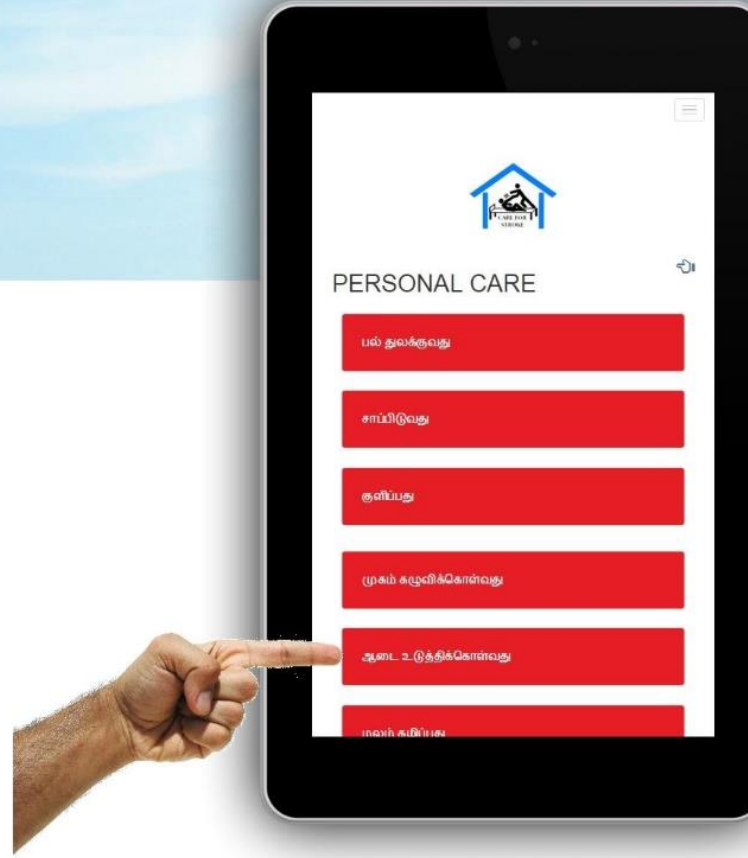
செல் போனில் சுட்டி காட்டப்பட்டுள்ள சின்னத்தை
தொடவும்

4



**செல் போனில் காணும் படங்களில் உங்களுக்கு தேவையான
ஒன்றை தொடவும்**

5



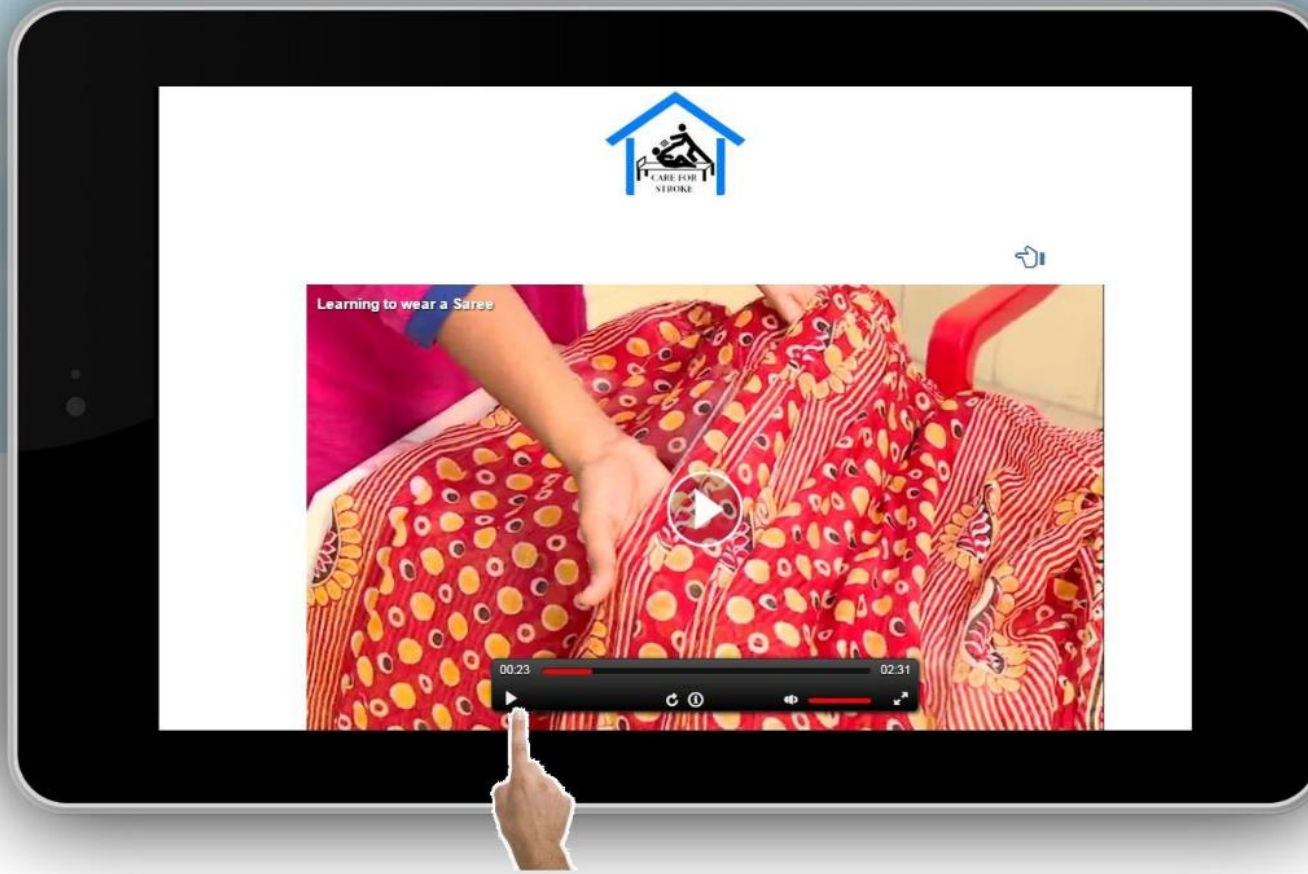
**செல் போனில் காணும் விஷயங்களில் உங்களுக்கு
தேவையான ஒன்றை தொடவும்**

6



**செல் போனில் காணும் படங்களில் உங்களுக்கு தேவையான
ஒன்றை தொடவும்**

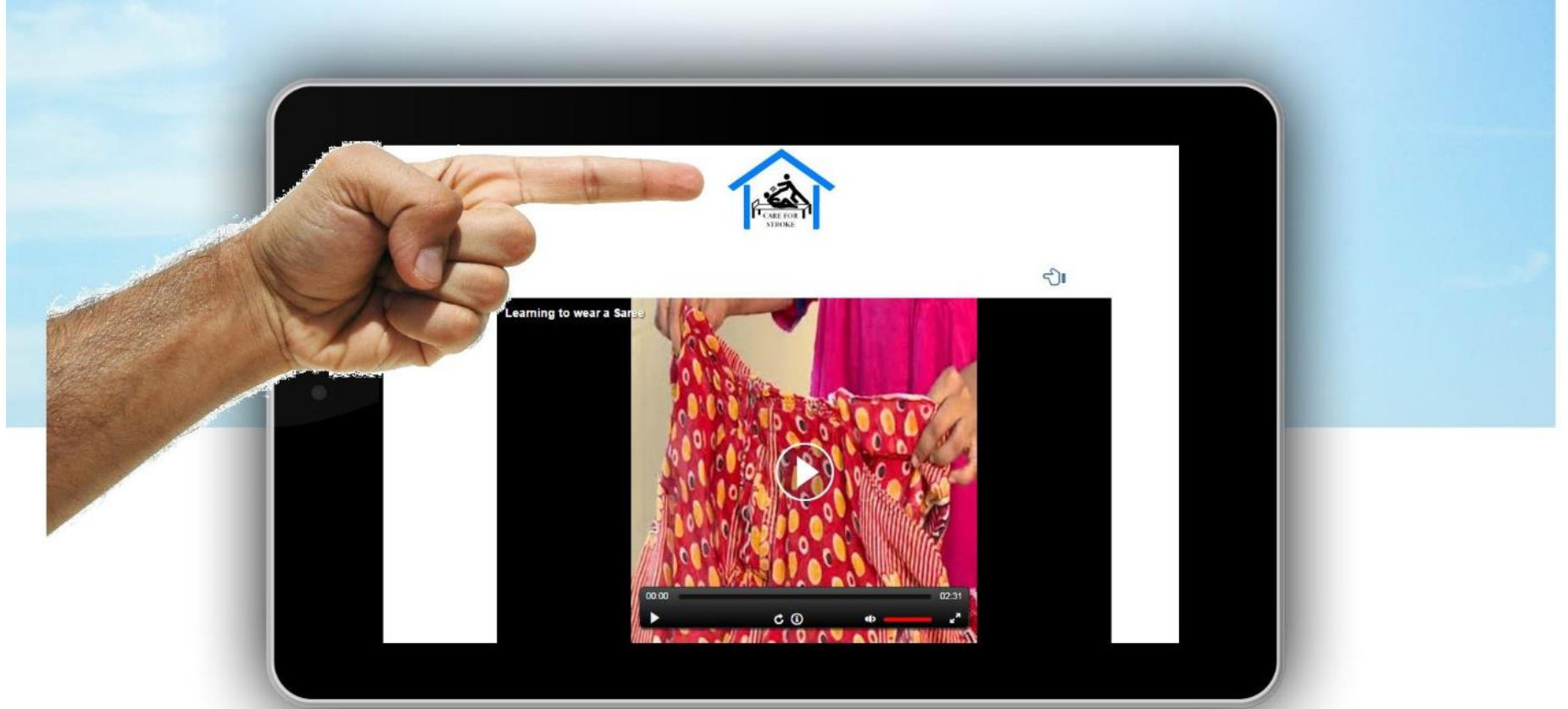
7



செல் போனில் சுட்டி காட்டப்பட்டுள்ள சின்னத்தை
தொட்டு நீங்கள் தேர்ந்தெடுத்த குறும்படத்தை காணவும்



**நீங்கள் பார்த்த முந்தைய பக்கத்திற்கு செல்ல சுட்டிக்காட்ட
பட்டுள்ள சின்னத்தை தொடவும்**



முதல் பக்கத்துக்கு செல்ல சுட்டிக்காட்டப்பட்டுள்ள
சின்னத்தை தொடவும்

Enclosure